

**LABOURING FOR BREATH:
LIVED EXPERIENCE OF CHRONIC BREATHLESSNESS IN
RURAL BANGLADESH**

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Summary

This ethnography explores experiences of chronic illness in a rural Bangladeshi village, examining the factors that contribute to people's experiences of unending illness.

Anthropologists have mainly studied chronic illness in wealthy countries, or in contexts where formal medical care was readily available. However, far less ethnographic attention has been directed toward the ways individuals living with excruciating poverty experience chronic illness. This thesis examines poor people's discourses of chronic breathlessness in rural Bangladesh, seeking to explore the lived experience of people who not only suffer from extreme poverty but also lack access to trained medical practitioners. The thesis argues that these rural sufferers of chronic breathlessness do not experience the illness itself as chronic. Rather, what dominated their illness experiences was a social situation characterised by the chronic presence of poverty, frustration, and disappointment. In this context, any illness, including chronic breathlessness, appeared as an episodic intensification or additional layer of suffering. Cultural and social norms also intensify the stigma surrounding chronic breathlessness, and this is particularly true in the case of vulnerable groups including women, the elderly, the landless, and those who lack supportive kin networks. Understanding the experience of chronic illness in rural Bangladesh demands that the illness experience is understood holistically. This means situating chronic breathlessness within the context of local cultural norms and social networks, as well as the broader local and national politics that produce a system of biomedical care that is beyond the reach of most poor villagers.

Statement by Author

I, Anupom Roy, state that this thesis has not been submitted for a higher degree to any other university or institution other than Macquarie University. I have composed this thesis based on my fieldwork data and literature review. I have duly acknowledged all of the sources. I have obtained ethical approval for this research from the Macquarie University Human Research Ethics Committee (5201000573).

Anupom Roy_____

Date_____

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Abbreviations

WHO	World Health Organization
DGHSB	Directorate General of Health Services
COPD	Chronic Obstructive Pulmonary Disease
WEF	World Economic Forum
UNFPA	United Nations Population Fund
NIDCH	National Institute of Diseases of Chest and Hospital
ICDDR,B	International Centre for Diarrhoeal Disease Research, Bangladesh

Chapter One

Introduction

It was 2a.m. on an early summer morning, and I had only just gone to bed when I was roused by the sound of someone banging on my door. I heard someone calling, “O *daktor* [doctor]...O *daktor*... please come for a minute.” As the banging persisted, I sat up and reached for the light switch only to find there was no power. I was not surprised by this discovery, as interruption to the electricity supply is such a common feature of everyday life in the village that I had long since stopped paying any particular attention to it. Bangladesh generates far less electricity than the country needs, and newspapers regularly report on power crises as common occurrences all over the country, irrespective of their urban or rural location. During my fieldwork, however, I was struck by the difference in the extent of power cuts between urban and rural areas. At various times, I lived in district towns of Netrakona and Dhaka. In Dhaka city, I experienced electricity disruption two to three times a day and each time it would last two to four hours. However, in Jalshiri village of Netrakona, I experienced power cuts five or six times a day, and each time they lasted for five to ten hours or even more. Often, the battery in my laptop ran down and I was forced to wait for several hours for the electricity to return. After each blackout, it was impossible to predict when the supply would resume. Sometimes the entire area surrounding the village was completely without power for more than a week, particularly if there had been a storm or strong wind. And, if severe windy weather damaged an electric pole, it often took several days for the electricity to resume as the villagers had to wait for a technician to arrive from the city.

On this particular night, I remembered to turn off the lights before going to bed, a sign that the electricity was cut whilst I was asleep. As I searched for a candle, I was sweating profusely from the summer heat. I kept thinking that I should have chosen to use a kerosene

lantern rather than a candle. In many village households, a kerosene lantern is kept beside the bed, with the flame dimmed. If the lantern is needed during the night it is a simple matter of turning up the flame to find one's way in the dark. By the time I reached the table and lit the candle, the banging on my door had stopped. When I opened the door, there was no one outside. I was surprised, however, to see Jharna's main door open at such an odd time. Jharna, a woman in her fifties, lived along with her husband and two sons on the other side of my courtyard. I heard some loud voices coming from the house. After reaching there, I saw Jharna gasping for breath. Her body was bent like a bow, and she was trying to breathe while keeping her mouth wide open. She was restless. One moment she was grabbing herself a pillow and next she was throwing her body into the bed. She was unable to hold steadily. Her throat was emitting a fearful whistling sound. "That's not good," I said to myself. As an asthma sufferer, I know this whistling sound to be extremely alarming as this symptom often prevents me from taking inhaler puffs properly, and prolongs my wheezing experience.

The nearest healthcare centre was a four-hour journey away, and the only form of transport at this time of the year was a boat. Yet it was impossible to hire a boat at this hour, because all the boatmen had gone home and would not return to the jetty until morning. Also, because this particular healthcare centre mostly provided primary healthcare and did not have emergency medical services, there was little point taking her there. The only place she could get emergency medical services would be one of the hospitals in the city. But taking her to the city was out of the question, as the journey itself took almost half a day, and included several modes of transportation. Thus, there was little I could do except comfort her by saying to keep calm – something that I find useful – and show her how to use the inhaler properly.

In knocking on my door in the night, Jharna had expected that I would have some medications that would cure her illness. Why did she ignore the fact – which I had stressed during our first meeting – that I was not a physician? What drove her to believe that there was

a permanent cure for her chronic breathing difficulty? How did the absence of formal physicians affect the regular management of chronic illness in such a remote social context? How did people in this village conceptualise the continuous nature of their suffering in their marginalised life situations?

This thesis is an ethnographic study of a chronic illness in Bangladesh. Although numerous studies address infectious conditions in this context, studies focusing on chronic illness are scarce. This indifference is probably related to the longstanding (erroneous) assumption that poor countries are yet to face the burden of chronic illness. This study investigates people's experience of chronic breathlessness in a remote Bangladeshi village, aiming to explore how the experience of poverty interacts with the experience of chronic illness. Rather than focusing on the biomedical conceptualisation and diagnosis of chronic respiratory conditions such as asthma, I am here concerned with lay people's understanding of the chronic experience of breathlessness. The clinical reality of illness experience is not the subject matter of this study; instead, it deals with the social implications of individuals' clinical encounters. Furthermore, unlike many studies that explore how ecological and environmental factors impact people's experience of respiratory illness, my focus is on the influence of social and structural realities upon the experience of chronic illness (Singer and Baer 1995).

How it began

My experience of living with asthma for more than a decade taught me to make several changes in my everyday lifestyle. One of the changes was to carry an inhaler. During my MA research project on tobacco use in Bangladesh, I was struck by the strong reactions of my informants when they would see me use my inhaler. The fearful look on their faces often embarrassed me. Sometimes I observed a sign of pity in their look; sometimes they became

too reserved to continue freely with the conversation. I came to realise that my breathlessness might adversely affect the interview processes and decided to modify my use of the inhaler. In order to avoid wheezing during my interview conversations, I developed a habit of taking a few puffs of the inhaler before I went to see someone.

It was around this time that I became curious about chronic respiratory illness. I discovered that there did not seem to be a straightforward consensus regarding the biomedical explanations of the condition. With many overlapping symptoms, there are a plethora of biomedical terms such as chronic obstructive airways disease, chronic airflow limitation, chronic obstructive pulmonary disease (COPD), chronic obstructive bronchitis, emphysema, and asthma that refer to chronic respiratory illness (Williams 1989; 1993:1-7). However, in popular discourse, indeed in most public health literature nowadays, there is extensive use of the terms asthma and COPD.

Most literature published by the World Health Organization (WHO) on chronic illness tends to focus on asthma and COPD when discussing chronic respiratory illness (DGHSB and WHO 2007; WHO 2011). The WHO explains asthma as “recurrent attacks of breathlessness and wheezing.” When a person experiences an asthma attack, the inner lining of his/her bronchial tubes becomes swollen, obstructing the air from passing in and out of the lungs. Globally, 300 million people suffer from asthma, 250,000 deaths occur due to asthma; and more than 80 per cent of all asthma related deaths occur in poor countries (WHO 2007: 15; WHO 2013a). Although Bangladesh lacks comprehensive data on asthma prevalence, an epidemiological study recently found asthma to be one of the major causes of childhood morbidity (Zaman, et al. 2007).

COPD, again following the WHO, is “an umbrella term” that refers to a variety of chronic lung diseases including emphysema and chronic bronchitis. When explaining COPD,

the WHO lists symptoms such as breathlessness, an excess of sputum, and chronic cough. The WHO considers COPD a “life threatening lung disease that may progressively lead to death.” Currently, 64 million people globally suffer from COPD, and by 2030, COPD will be the third leading cause of death in the world (WHO 2013b). Again, there is no nationwide data on COPD in Bangladesh. One report speculates that NIDCH, the only tertiary referral hospital for chest disease in the country, annually admits around 4500 to the department of respiratory medicine and 19 per cent of those admissions are related to COPD (DGHSB and WHO 2007). Another report postulates that among the general population aged thirty or more, the prevalence of COPD is 3 per cent (WHO 2005).

My desire to explore chronic respiratory illness also led me to discover that the global prevalence of chronic illness is extraordinarily high. Indeed, chronic illness is expected to cause 41 million global deaths by 2015 (Strong, et al. 2005). Yet these health conditions can only be managed, they cannot be cured. The most common conditions include cardiovascular disease, cancer, diabetes, and chronic respiratory illness (WHO 2011). Out of 57 million reported deaths in 2008, 36 million (63%) occurred due to chronic illnesses, which included cardiovascular condition (17 million), cancer (7.6 million), chronic respiratory illness (4.2 million), and diabetes (1.3 million) (ibid.). Another report estimated that out of every ten current deaths, six occur from chronic, three from infectious illness, and one from injuries (WHO 2009a). These statistics are cause for concern, perhaps more so due to the uneven distribution of the disease burden across “developed” and “developing” countries. In the next decade, developing countries are expected to see a decrease of three per cent in the prevalence of infectious conditions, whereas chronic illnesses are expected to increase by 71 per cent within the same period of time (WEF 2010: 25). Developing countries, with the exception of African countries, already have a high prevalence of chronic illness that outweighs their prevalence of infectious conditions. In Africa too, deaths from chronic illness are expected to

supersede the number of deaths from infectious condition by 2030 (WHO 2011). Overall, the developing countries currently share 80 per cent of the total global deaths from chronic illness (ibid.: 1).

There is an impressive range of anthropological literature addressing various chronic illnesses in different parts of the world (Wiedman 1987; Kaufman 1988; Estroff 1993; Dressler, et al. 1995; Garro 1995; Becker 1997; Hunt 2000; Rose and Manderson 2000; Reis 2001; Van Dongen 2001; Greene 2004; Schwartz 2004; Van Sickle 2004; Schoenberg, et al. 2005; Whitmarsh 2008a; Mattingly 2010; Mendenhall, et al. 2010; Gregg 2011; Broom and Doron 2012; Trnka and McLauchlan 2012; Whyte 2012). Surprisingly, even though developing countries bear most of the burden of chronic illness, there has been relatively scant attention to these contexts in the anthropological investigation of chronic illness. With the exception of a few (Van Sickle 2004; Broom and Doron 2012; Whyte 2012), most of the studies have been undertaken in high-income countries. Further, these studies pay meagre attention to the relationship between poverty and chronic illness (except for Schwartz and Pepper 2009). Thus, with this ethnography, I aim to contribute to the small but growing body of literature on chronic illness in poor countries.

The ethnography

To understand how this ethnography speaks to the current anthropological scholarship on chronic illness, at least four aspects of chronic illness experience need to be examined: (a) narrative formation, (b) lay conceptualisation, (c) therapeutic experience, and (d) medical system. I will briefly introduce these terms and describe the orientation of the thesis towards each of them.

Narrative formation

Previously, scholars paid particular attention to the importance of narrative formation among individuals with chronic illness. Individuals develop their narratives as a way to make sense of the uncertainties and to deal with the overarching impacts of the chronic conditions in their lives (Becker 1997; Mattingly and Garro 2000). Narrative development helps them to re-construct their sense of self, a process that enables them to make sense of the ambiguities that accompany the non-ending nature of their illness. Individuals also use narrative as a way to deal with society's negativity towards the illness. Among cancer patients, for example, narratives may be generated in a strategic manner that emphasises their past social roles in order to avoid stigma associated with cancer (Hunt 2000; Gregg 2011). My informants also narrated their stories in a strategic way to avoid local stigma associated with chronic breathlessness. However, I found that these strategies involved a re-appropriation of local illness terminologies rather than a re-conceptualisation of the past social roles. They brought some terminologies in their narratives, which did not directly refer to chronic breathlessness but still explained the symptoms associated with breathlessness in a non-stigmatised form.

Lay conceptualisation

The dominant view of chronic illness in public health and medical literature conceptualises the development of chronic illness in terms of various behavioural characteristics (such as smoking) (DGHSB and WHO 2007; WHO 2011). Scholars from anthropology and sociology have called for an examination of the social realities that produce these behaviours (Ware, et al. 1992; Lupton 1993). In Bangladesh, for example, many of the poorest labourers smoke *bidis* (filter-less cigarettes) in lieu of breakfast because cigarettes are cheaper than food and suppress the appetite when people cannot afford to eat (Roy 2012). In such a context, the choices of individuals cannot be separated from the excruciating poverty, and the class structure that condition tobacco use in Bangladesh. Consequently, in order to

gain a greater understanding of chronic illness, many researchers have urged that we follow the experiences of individuals at the local level (Ware, et al. 1992; Christakis, et al. 1994; Manderson and Smith-Morris 2010b).

In her study on diabetes in a Canadian aboriginal community, Garro (1995) found that her informants explained their illness as a consequence of their contact with Europeans. They considered the inclusion of junk food and canned food in their lives to be responsible for many of their ailments, including diabetes, and explained these dietary changes as a phenomenon of the post-European period. Others have also shown that individuals refer to their personal histories in order to explain the development of their diabetes, focusing on distressing experiences and the social suffering they have endured (Hunt, et al. 1998; Schoenberg, et al. 2005; Mendenhall, et al. 2010). Similarly, my informants also sought to make sense of their chronic breathlessness through the trajectories of their personal lives, and placed particular emphasis on their lifelong experience of overwork.

Therapeutic experience

The use of various therapies constitutes a major component of the experience of chronic illness. Researchers have explored the moral and cultural dimensions that determine therapeutic experience. Becker and colleagues, for example, show how American cultural notions of individual bodily control may prevent individuals with asthma from seeking emergency medical care at the time of a serious illness event (Becker, et al. 1993). Another study explores how cultural notions of age influence people's perception of recovery from stroke (Becker and Kaufman 1995). Dressler (1980) also explores how ethno-medical beliefs can discourage individuals with hypertension from seeking biomedical care and encourages them to make use of remedies that are more consistent with local cultural beliefs.

A different set of studies emphasise the structural constraints on individuals' lives to see how they determine therapeutic experience. Hunt and colleagues, for example, show that their informants ceased consuming medications because the medications often required an alternation in everyday lifestyles (Hunt, et al. 1989). Similarly, Greene (2004) criticises over-emphasis on cultural factors, showing that structural factors (such as hidden costs in healthcare) associated with treatment regimens discourage individuals from consuming medications.

In many scholarly works, there has been an implicit suggestion that cultural and structural factors need to be explored simultaneously. And yet, few studies have attempted to bridge this theoretical gap. The stories of my informants, however, demonstrate how both cultural and structural factors closely intersect with one another. In the narratives they tell of their lives, it is difficult to conceptualise these factors independently. Thus, I argue that *both* factors play crucial roles in their experience of illness, as well as their discourses about their therapeutic trajectories.

Medical systems

Biomedicine is the state-sponsored and therefore dominant medical system in most countries, including Bangladesh. Researchers have explored how principles of biomedicine and broader factors relating to biomedical systems affect the experience of chronic illness. Studies show that biomedicine's ambiguous and often contradictory definitions of asthma greatly exacerbate individuals' suffering as enormous confusion surrounds their perceptions of the diagnosis (Rose and Manderson 2000; Schwartz 2004). Also, as Whitmarsh (2009) shows, an over-emphasis on the notion of compliance in the biomedical system may produce a haphazard use of medications among individuals with asthma. He describes how the misuse of medication can be an antagonistic reaction to the biomedical "obsession" with compliance. Unlike earlier studies, the context of my ethnography lacked the presence of a full-fledged

formal biomedical system. There were no clinics, hospitals or trained medical practitioners nearby where my informants resided.

Scholars have also explored how broader socio-structural factors of biomedicine may influence people's perceptions of chronic illness. In South India, Van Sickle (2004) explores how multiple factors contribute to the development of socio-cultural meanings of asthma, including promotions of leading drug companies, as well as popular media. Similarly, Whitmarsh (2008a; 2008b) investigates how, in Barbados, a nexus between international biomedical research, pharmaceutical companies, and government agencies contributes to a vagueness in people's perceptions of asthma and eventually result in the over-diagnosis of the disease. In my study, however, rather than investigating the impact of such broad social factors associated with medical systems, I examine how people understand and interpret their exclusion from the broader institutionalised biomedical system.

Overall, the aim of this ethnography is to examine the variety of factors that affect the experience of chronic breathlessness in a remote Bangladeshi village. Previous ethnographies of chronic conditions in Bangladesh include studies of childlessness (Nahar 2007), arsenic contamination (Islam 2010), and mental illness (Wilce 2004). This is first ethnography of Bangladeshi society that examines chronic respiratory conditions, which is one of the four common chronic illnesses that make up the vast bulk of chronic illness related mortality and morbidity.

Outline of the chapters

In chapter 2, I present a brief reflexive account on conducting ethnography in one's own cultural context. I describe some basic social, demographic, and infrastructural features of the village where I conducted this research. I also explain my methodological strategies such as how I built rapport with my informants, as well as how I collected, analysed and

interpreted information. Chapter 3 begins with a description of local socio-cultural perceptions of chronic breathlessness. I describe how chronic breathlessness is associated with social stigma, and explain how my informants strategically used their illness narratives to re-create an alternative, non-stigmatised illness identity. In chapter 4, I describe how my informants explain the development of their chronic breathlessness through particular social practices. I explain how they present their everyday frustrations and disappointments through their explanation of the illness. Chapter 5 deals with their therapeutic experiences. The chapter explains how a combination of various social factors that promotes hope for a permanent cure eventually drives my informants' therapeutic trajectories. In chapter 6, I explain the critical roles of the local untrained medical practitioners and elaborate on their particular ethics of care that enabled my informants to receive medical treatment. I also discuss their interpretations of the existing geo-political divisions in the country's healthcare system. In the conclusion, I integrate all of these disparate strands of theory to ask what the ethnographic data presented in this case study of chronic breathlessness in Bangladesh can contribute to critical medical anthropology.

Chapter Two

The Place and the People

The discussion in this chapter deals with the methodological aspects of this ethnography. I elaborate on various techniques that I used for collecting, analysing and interpreting the data. The chapter also contains a reflexive account of my experience in conducting the study in my own culture.

Either boat or foot

Where are you from? I find this a commonly asked question in Australia, maybe because the society is composed of many immigrants from various culture and nationalities; thus, people ask this question in everyday conversation to elicit one another's background. When an Australian colleague asks me this question, my answer is usually a simple one, "Bangladesh," which seems to satisfy the questioner too. However, my uneasiness about this question arises when a fellow Bangladeshi asks me the same question. When speaking with another Bangladeshi, the way I explain my background varies greatly. I find that I adjust my response depending on where our conversation is taking place (i.e., whether we meet in a large divisional town or in a small district town nearby mine), and also their geographical knowledge of the country. The primary reason for my confusion has to do with the apparent ambiguities that underpin the intention of the question. Does s/he want to know where I was born? Where I grew up? Where my parents lived? The location I identify myself with? What should my response be if I have a different answer for each of these questions?

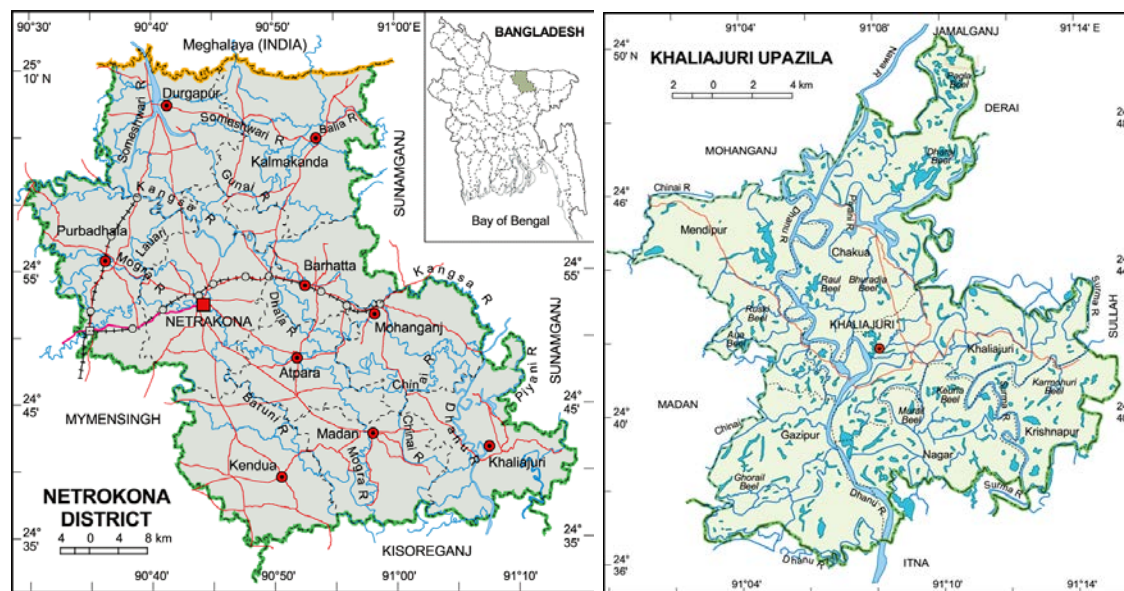
I am a Bangladeshi by birth. Bangladesh, with more than 160 million people occupying an area of 147,570 km², and more than 80 per cent of the total population earning less than two dollars a day, is one of the most populous and poorest countries in the world

(UNFPA 2009). There is presently a great deal of discussion about extreme poverty and hunger in the country (see Van Schendel 1986; Maloney 1988). Was it always this way? Six hundred years ago, Ibn Battuta, a Moroccan traveller who extensively travelled through Persia, China, Sumatra and Timbuktu, was so impressed by Bengal that he wrote, “This is a country of great extent, and one in which rice is extremely abundant. Indeed, I have seen no region of the earth in which provisions are so plentiful” (Hartmann and Boyce 1983: 11). Many historians have demonstrated how six hundred years of wealth depletion by several colonial regimes have transformed the place from the land of abundance that Ibn Battuta describes to one of the poorest places on earth (see for example, Dutt 1902; Dutt 1904; Sen Gupta 1974).

Bangladesh shares a geographical boundary with India. With the exception of the south of the country, which is surrounded by the largest bay in the world, the Bay of Bengal, the north, west, and east sides of the country are bordered by India. Bangladesh also shares a small area of its south-eastern border with Myanmar. Ethnically, more than ninety-eight per cent of the people are Bengalis, a branch of Indo-Aryans. A few minority indigenous communities (1.10%) live in parts of the south, north, and north-eastern areas, most of whom belong to Sino-Tibetan descent (Zaman 2005). Major religions include Islam (90%), Hindu (9%), Buddha (0.7%), and Christian (0.3%) (Lewis 2011: 25). There are seven administrative divisions. Each division is divided into several districts with a total of sixty-four districts. The districts are further sub-divided into sub-districts, wards, unions, and villages.

My village, Jalshiri (a pseudonym), belongs to the Khaliajuri subdistrict of a north-eastern district named Netrakona. According to the 2011 national census, Netrakona has an area of 2794.28 sq. km. and a population of 2, 229,642. Khaliajuri has an area of 297.63 sq. km. and a population of 97,450. Jalshiri is one of the seventy-five villages under Khaliajuri subdistrict. Jalshiri is particularly known in the area because of a rural bazaar next to the village. Even though rural bazaars are the centres of economic transactions for the people, not

every village has a bazaar. As the bazaar next to Jalshiri is one of the largest and permanent bazaars in the area, people from more than twenty villages regularly come to this bazaar for their regular needs. Even though some villagers of Jalshiri own shops in the bazaar, their principal livelihoods come from the cultivation of rice paddy.



Picture 1: Netrakona District and Khaliajuri *upazila* (sub-district)¹

Apart from being principally an agrarian economy, the area is also very remote and lacks necessary infrastructure. The district-government's online portal describes the area as “a scattered island-like place with no direct road communication to the district town” (Netrakona Zila 2013). This statement is indicative of the remoteness of the area. Every year during the rainy season, the entire area becomes inundated by floodwater running from the highlands near the Himalayas, an event that changes the entire landscape. The flood abolishes all the small canals and estuaries, transforming the area into a marshland. The villages appear as small, sporadic islands surrounded by vast expanses of water. During this time, canoes and locally built engine driven boats are the only mode of transport. After about three month, the water starts to go down and the dry season draws near. At this time of year, the principal

¹ I have adopted these two maps from Banglapedia – the National Encyclopaedia of Bangladesh (Islam 2013)

method of transportation is walking. Even though a few villagers own bicycles and motorbikes, the use of such vehicles is limited by the sporadic presence of small estuaries.



Picture 2: When water engulfs everything

My grandmother used to call me “a lucky child” because I “saw electricity” as soon as I came into this world. All of her children “saw just a kerosene lantern” after they were born. She even lost one of her baby girls shortly after her birth, as no medical support was available. I have heard incredible stories of how people in the area used to travel. Just 50 years ago, one had to travel nearly two days – including more than a day of walking – to reach Netrakona town. When I was a primary school student in the 90s, the villagers walked for 6 to 7 hours before catching other forms of transport. As I walked the paths of my childhood in the course of fieldwork, I recalled riding on my father’s shoulder as a child. I used to become restless, so my father would keep pointing to the next distant, faded shape of a village, all the time reassuring me that we were “almost there.” This helped me remain cheerful. Now I think how

hard it must have been for my father to carry me on his shoulders for several hours. Today, the villagers do not have to walk more than two hours before they reach other forms of transport.

Even though communication has improved, the Jalshiri people still struggle unimaginably in cases of emergency situation. In cases of emergency during the rainy season, a villager has to hire a boat to travel to a nearby subdistrict before catching a bus or train to the city. In many cases, the ill person dies before reaching to the city. Although one can hire a boat in the rainy season, emergency travel becomes almost impossible in the dry season. The dilemmas presented by the remote location of Jalshiri are apparent in the case of medical emergencies, when people have no ready access to proper medical treatment. There is only one small, under-staffed, and under-resourced government healthcare centre in Khaliajuri sub-district centre, which mostly provides primary healthcare services. Furthermore, those who live in places other than close to the subdistrict centre have to spend almost the whole day waiting to receive treatment from the healthcare centre. I noticed that among my informants, this healthcare centre was the last place they would seek treatment. In fact, in most cases, the villagers of Jalshiri are forced to consult untrained medical practitioners in the village bazaar. The only way to reach a trained physician is to travel to Netrakona town, or another adjacent subdistrict, a journey that is impeded by poor infrastructure and the people's marginalised economic condition.

So, when my grandmother called me “a lucky child”, she was using “the light of electricity” as a metaphor. She was probably reflecting upon the hurdles and uncertainties entailed in life in the village. She may have meant that I was lucky to have a physician beside me when I was born; something made possible by the fact that my father was financially capable of taking care of my mother and I during my infancy. Or maybe she was referring to the precautions my father had taken against any potentially unlucky circumstances that might

occur during my birth. I “saw electricity” because a few weeks before the delivery, my father sent my mother to Mymensingh, a large district nearby. The city of Mymensingh has one government hospital, one private teaching hospital, and numerous private clinics. Often people from adjacent districts, like Netrakona, go there in search of better medical care. My mother told me that I caught a severe bronchitis infection as an infant, but instant medical help saved me. My birth in a city hospital probably determined my fate – I would remain an occasional “traveller” to my own village for the rest of my life.



Picture 3: Winter landscape

When I was five, my father sent me to Netrakona town to live with an aunt. He wanted me to receive a good education, which unfortunately the village lacked. I lived in Netrakona until the 12th grade. My father visited me periodically, usually every fortnight; I visited my village, usually once a year at the end of my school final examination. The frequencies of my visits to the village reduced after I moved to an eastern divisional town for my undergraduate

education. Around this time, the village received its electricity connection, a thing that many people previously never thought possible. After graduation, I moved to Dhaka in search of a job. Dhaka is not only the capital; it is the largest and most urbanised city in the country. Living in all these places also meant that I never had a chance to live in the village for an extended period of time. As a result, I became an unfamiliar face to the villagers and most of them do not recognise me until I mention my father's name.

The reflexive thoughts in this personal account, I believe, have undoubtedly affected the whole experience and outcome of this ethnography (for a discussion on how reflexivity shapes ethnography see Brewer 2000: 126-133). In this account I have also introduced the names of five places (Jalshiri, Khaliajuri, Netrakona, Mymensingh, and Dhaka), which recur throughout my discussion in this thesis.

The Fieldwork

Conducting fieldwork is one of the most important aspects in the discipline of anthropology. Fieldwork is so important that some term it “a rite of passage” essential to becoming an anthropologist (Gupta and Ferguson 1992: 16). Many have critiqued the concept of “the field” in recent decades. The traditional conception of “the field,” derived from classical anthropological research, has several flaws in its applicability to contemporary anthropology. In classical anthropology, “the field” was a remote place to which anthropologists travelled to document an “exotic” culture, a perception that may be seen as ethnocentric. The concept of “the field” was based upon the perception of place as a geographically bounded location. In other words, it was culture located in a distant site waiting to be discovered by anthropologists. Various factors such as migration, globalisation, and the post-colonial context have weakened the previous spatial notion of “the field” as the boundaries between various cultures have become blurred and contested (Gupta and Ferguson

1992; Bhabha 1994). Thus, contemporary anthropologists have encouraged a re-conceptualisation of this spatial notion of “the field.”

In mid-2010, I received the final approval from the Macquarie University Human Research Ethics Committee for this research. In principle, one cannot carry out research without first gaining the approval of the ethics committee. But when I think about this, it puzzles me as I have no specific date for when my fieldwork began; certainly it has not ended although I am writing about those experiences now. I ask myself, did not my “journey” to “the field” – in Bangladesh as opposed to Jalshiri – actually start when I was born? What about my periodic visits to the village? What about my experience of conducting the MA research in the same area? Much of the data I collected for this present study, even though it was collected following my ethics approval, has strong roots in my earlier visits to the area. How could I keep all the experiences I had accumulated over time locked in my mind before embarking upon the most important project of my life in the place that I call home (Lederman 2006)? In fact, for an ethnographer, it is impossible to do so because of the very nature of the investigation itself, where the ethnographer’s multiple social identities (personal, academic, etc.) routinely intersect with one another.

My use of the term “home” here refers to a variety of things: my village of Jalshiri, my district of Netrakona, and my country Bangladesh. For the sake of the discussion, although I am calling Jalshiri my “field,” the field for this research was actually Bangladesh albeit in a non-specific sense. I spent most of my 18 months of fieldwork among the villagers of Jalshiri. When I found my rural informants strongly believing that a permanent cure for their breathlessness was in Dhaka, I decided to talk to some of the poor people who sought medical treatment in Dhaka for chronic breathlessness. I was interested to see if they also held similar perceptions. The data that I gathered from Dhaka cannot be termed as something that came from a different field, as the trajectories of my quest were the same; that is, I wished to

explore how socio-structural factors influence the illness experiences of socio-economically marginalised peoples (rather than collecting data in two different spatial sites).

At the outset, I was worried that I would overlook many aspects of my fieldwork data by taking them for granted. I wondered if familiarity would engender a lack of awareness of the minute details of the villagers' everyday lives. I thought of other fellow researchers in the department, who were preparing to undertake fieldwork in a culture other than their own. I pondered whether they were in a better position in terms of their ability to collect data. Perhaps they might glean insight through a simple hand gesture, which appeared as something new to their eyes, enabling them to explore this gesture further. Does pre-familiarity really increase the chances of overlooking ethnographic facts? Can one's pre-familiarity prove an advantage as well? Can it help an insider to conceptualise many complex and seemingly ambiguous cultural meanings quicker than an outsider?

Although being a Bangladeshi and a member of the local community were two assets in my fieldwork, I did not consider my pre-familiarity the most important tool. In fact, one who is doing research in own culture should not assume that the job will be easy, i.e., that he or she can avoid the long process of "familiarisation." The distance between scholars and their "target" villagers is always present (Okely 1984; Shamsul 1982 in Strathern 1987). This project taught me to critically observe my pre-familiarity with the rural Bengali culture and how to use it to enhance the fieldwork experience (Van Dongen and Fainzang 1998).

Some personal strategies that I came up with based upon my pre-familiarities of the core elements of the local culture (such as kinship, gender, and religion) have extensively assisted me in developing rapport with the people of Jalshiri. For example, even though I was able to develop good conversations with my prospective informants quite early, I stumbled whenever I wanted to expand the conversation into a deeper ethnographic interview.

Whenever I asked them about *hapani* (the local term for chronic breathlessness), it seemed to me that they either withdrew from the conversation or responded reluctantly. I sensed a hesitance and unwillingness on their part to continue the discussion any further. The following excerpt is from one of those incomplete conversations. In this instance, I went to meet an elderly man named Emdad after I heard about his chronic breathlessness from others:

Anu: Aslam-alaikum, *Chacha* (uncle). How are you?

E: Woalaikumassalam

Anu: *Chacha*, my name is Anupom. I study in an Australian university.

E: Good. Very good, come, sit here. How long have you been living there (in Australia)?

Anu: *Chacha*, a few years.

E: Good. Why did you come back?

Anu: I am a student in Australia. As a part of my study, I am trying to know people's experience of *hapani*. I am trying to know more about this illness

E: Hmm, this disease is very bad. There are many people in this village who suffer from this. You should speak to kamal. It is long time since he has this illness.

Then, in a curious tone he asked: Do you give medicines too?

Anu: No *chacha*, I am not a doctor. I am researching about how people experience and manage the illness and what impact this illness has on one's life.

E: Oh!

Anu: I heard that you have had *hapani*...?

E: Hmm...cold problem. I am getting old you know. So, the cold attacks me quickly. Are you going to the bazaar now? Your aunty will be angry with me if I am late. I have to go to the bazaar. (You should) come and visit us sometime. OK?

For several days, I did not realise what went wrong with this conversation. I knew that I addressed him in accordance with the social hierarchy. Yet, he did not want to continue the conversation. Yes, it was quite possible that he was busy and needed to go to the bazaar. However, I had similar incomplete interactions with a few others. As I came to understand more about local understandings of the illness, I realised there was a high level of stigma associated with the condition. Because of the extreme negativity attached to the illness, the

terms that directly referred to the illness were also stigmatised. The sufferers and their close relatives often tried to avoid using such terms in their conversations about the illness.

In my initial interview attempts, I was unable to understand my informants' urge to avoid stigmatised terminologies. In the excerpt above, for example, I made at least two mistakes: first, I should not have used the word *hapani*, even though the term was the appropriate Bengali word for chronic breathlessness. The term was stigmatised. Second, I failed to pick up the informant's attempt to use "cold problem" as an alternative term to refer to his ailment. Understanding this particular cultural meaning of the illness and individuals' subjective coping strategies in an early period of my fieldwork saved me from a methodological disaster.

Another aspect that I should also emphasise from the excerpt is the use of kin terms, a common characteristic in Bengali culture that serves many purposes in everyday interactions (Rozario 1992: 64-66; Inden and Nicholas 2005). When I spoke to the villagers, I carefully chose an appropriate kin term that coincided with the local social hierarchies of age and gender. Use of kin terms is one of the commonly observed practices in the everyday lives of Bangladeshis, especially in rural villages. One's age and gender are the two key determinants for coming up with an appropriate kin term for the person. The villagers used kin terms in everyday conversations in order to enhance interactions. When I walked around the village bazaar, I frequently heard people calling each other brother, uncle or any other locally appropriate kin term. While use of positive and respectful kin terms enhances interactions, inappropriate terms may also have disastrous effects upon the interactions. An outsider who is not familiar with this social practice might find the frequent use of kin terms deceptive. However, to the villagers, appropriate use of kin terms reflected camaraderie, care and respect. Thus, appropriate use of kin terms has not only helped my interactions with the villagers, but also greatly assisted in building rapport with them.

Here I describe another instance where use of appropriate kin terms facilitated my relationships with informants. The incident occurred during a meeting with elderly Ekram who suffered from chronic breathlessness. When I entered his house, I saw his wife Fuli standing next to the bed on which Ekram was lying. Next to her was a half-made fence made of bamboo strips. Seeing me, she quickly went to other side of the fence, hiding her face using the end of her sari as a veil. After Ekram told me that he was a friend to my late grandfather, I called him *dadu* (grandfather). While sitting on his bed, I saw Fuli carefully observing me. She was probably wondering what an unknown man was doing in her house. While addressing her as *dadi* (grandmother) I indicated the stool next to the bed and respectfully requested her to sit, saying: “*Dadi* (grandmother), come here please, sit here.” Clearly less hesitant than before, she came and sat on the stool.

I also noticed that I was sitting on a higher level from the ground (on the bed) than she was. As a younger person, it was my responsibility to make sure that as a mark of respect, she, the older person, sat in a higher position. Immediately, I got off the bed and politely requested her to sit on the bed instead. I asked her to give me the stool. Apparently, she was pleased with my respectful gesture and, adopting a somewhat mollified tone, she insisted that I remain sitting on the bed. Because of the existing social hierarchy, her insistence meant that she, as a senior member of the community, was granting permission to me, as her junior.

I cannot claim that everything I did in this instance was intentional. Most of it was probably intuitive, borne of my taken-for-granted understanding of the local culture (see Hayano 1979). And yet, it did not escape my attention that this small gesture from me brought a comfortable atmosphere into the room. Fuli became actively engaged in my conversation with Ekram. She was neither overtly careful about keeping her veil drawn across her face, nor was she hesitant about answering my questions. Thus, I found employing appropriate kin terminology with proper non-verbal gestures effective measures to indicate my respect for

existing social hierarchies of gender and age. I was rediscovering my pre-familiarity with the Bengali culture and using it strategically to enhance my experience of participant observation and to enrich my data collection.

Data collection

In the preface of Malinowski's classic work *Argonauts of the Western Pacific*, Sir J. G. Frazer wrote: "He sees man, so to say, in the round and not in the flat." This notion of "holism" derives from the concept that the researcher would live with and participate in the social lives of the local people for an extended period, in order to gain a holistic understanding about them (Malinowski 1922). Participant observation, which was the principal method of data collection in this project, has been the most crucial method utilised in anthropological fieldwork since the discipline's inception (Malinowski 1922; Radcliffe-Brown 1922).

The term "participant observation" implies that the researchers will participate in the social world of the group being studied. This is done in their natural setting while maintaining "a professional distance that allows adequate observation and [the] recording of data" (Fetterman 2010: 37). Participant observation involves not only documenting events and experiences of the informants, but also gaining an understanding of the local meanings associated with those events through immersion in the context of the informants' everyday lives. And in this way, the researcher's understanding of the topic of inquiry becomes more holistic and contextually meaningful (Brewer 2000; Wolcott 2005).

During fieldwork, some of the changes that I intentionally made to my lifestyle included wearing local clothing and using the local dialect. Even though I stopped wearing urban clothing and avoided using an urban dialect, I do not think my informants forgot my "outsider" identity – a person who was privileged to study and live in a foreign country. This sense of distancing is in fact not uncommon in ethnographic studies (see for example Burr

2009). This distancing may also be seen as a critique of the ideal notion of participant observation. In critiquing participant observation, some state that all social research involves participant observation as one cannot study a social phenomenon without being a part of it (Hammersley and Atkinson 1983: 16). Others even find participant observation “impossible,” “a dream” or “an ideal” because “true participation precludes the type of observation which is required of an anthropologist” (Van der Geest and Sarkodie 1998: 1373).

Although a large part of the data came from informal observation and conversations, I also conducted in-depth interviews. My initial plan for recruiting informants for in-depth interviews was to distribute pamphlets or posters containing information about the research. Salil (pseudonym²), my local research assistant, disagreed with this idea. According to him, this measure would appear as forms of “advertisement” and might create misunderstandings regarding our purpose. He stated that the villagers might perceive the pamphlets as “greedy advertisements” distributed by a medical practitioner seeking patients. The walls of rural shops were covered with numerous posters of urban clinics advertising many services they offered. The villagers usually held a strong negative perception about those advertisements.

Salil’s argument about the negative image of the pamphlets seemed convincing to me. Instead, I decided to recruit informants through personal communications and word of mouth. Because Salil’s father also suffered from chronic breathlessness, he already knew a few others who suffered from the same illness. Salil and I spoke to several villagers and local medical practitioners to get information about prospective informants. After we heard of someone who suffered from chronic breathlessness, we both went to meet the person to introduce my research project and invite him or her to participate. Salil’s extraordinary communication skills impressed me many times. As we entered houses in the village, he would address people

² I have decided to use a pseudonym for this research assistant because his father was my informant. Revealing his name would likely make it possible to identify his father, even if I used a pseudonym for his father.

using local kin terms. This approach immediately created a comfortable atmosphere, though I did not use these first meetings to initiate in-depth interviews. Although Salil accompanied me to people's houses during most of my interviews, he never actually sat in on the interviews. Salil performed an important role in keeping the curious neighbours busily chatting outside the house, enabling my interview conversations to go ahead undisturbed.

A checklist of questions guided the forty-nine semi-structured, in-depth interviews I conducted as part of my fieldwork. The people with whom I conducted in-depth interviews included men and women with chronic breathlessness (34), their relatives (9), and local medical practitioners from the village bazaar (5). Each interview lasted between forty minutes to two hours. Based on the richness and importance of their stories, I also conducted in-depth case studies with seven of these people: three men and two women sufferers, and two local medical practitioners. Each case study consisted of multiple interactions of participant-observation over the period of my stay. In each case, I spent time at their homes and workplaces, so that I could get to know them at a deeper level and explore their lived experience more appropriately.

After observing the critical role of the local practitioners in the area, I became particularly interested in their medical practice. I discovered that urban medical representatives regularly visited the area and arranged training sessions to introduce their drugs to the practitioners. Several practitioners told me that those sessions were particularly useful for them to learn about new drugs and their appropriations. One practitioner helped me to attend one of these sessions, and this formed part of my observational data.

I had another research assistant named Mahmud who was an anthropology graduate. He assisted me during my short period of fieldwork in Dhaka. Together, we went through relevant literature at the libraries of the International Centre for Diarrhoeal Disease Research (ICDDR), the World Health Organization (WHO), the United Nations, and the National

Library. We examined papers on health policy, the healthcare system, chronic illness, inequalities in healthcare, and various measures taken in both the public and private health sectors to tackle chronic illness.

During my time in Dhaka, I also conducted six semi-structured interviews with individuals who suffered from asthma (three men and three women) at the government asthma centre in National Institute of Diseases of Chest and Hospital (NIDCH), Dhaka. These interviews were short in length and lasted between thirty minutes and one hour.

In addition to audiotaping all of the interviews and case studies of this research, I always carried a diary to take notes. I had the diary with me almost all of the time when I was out in the village, at the bazaar, or speaking to a prospective informant. I immediately jotted down anything I observed to be important. Every evening I elaborately recorded my observations of the day on my laptop using Microsoft Word and an open-source software named Avro to write in Bengali. Mahmud transcribed the six interviews with urban informants and I performed the rest of the transcriptions myself. Both of us transcribed the interviews in Bengali. During the analysis of the data, I translated them into English. My discussions with both of my research assistants were useful in thinking through the life experiences of the informants. The analysis process entailed situating the experiences of my informants in the context of their daily lives and personal histories. In doing so, I sought to avoid reducing their illness experiences to a list of symptoms and encounters with medical facilities.

In ethnographic research, the ethnographer is always a crucial data collection tool. Everything that the ethnographer sees, hears and observes can be considered data and may be used for analysis and interpretation. Because of their subjective involvement, anthropologists sometimes refer to themselves as “a human instrument” who, drawing upon their personal qualities, develop a close relationship with their informants and eventually find it easier to

collect necessary information (Burgess 1982; Fetterman 2010). This notion of subjectivity does not just begin or end when the researcher is interacting with the informants. Rather, this involvement also encompasses the ethnographer's own thoughts and involvement with other research instruments, such as a field diary, which eventually impact the actual ethnographic evidence itself (Taussig 2011). I found this personal involvement to be particularly true of the experience of doing ethnography at "home".

Studying "home"

I began this chapter with a discussion of my reluctance to come up with a precise answer about my "home". A spatial criterion would probably direct me to two answers: one might say my "home" is Jalshiri as my parents lived there all their lives. I also see Jalshiri village as my "roots" because that is the place where my family has made its livelihood. Another view might see Netrakona district town as my "home" because I spent most of my childhood and youth there. None of these responses, however, seem satisfactory. Surely there is a major problem with this spatial categorisation of defining one's "nativity." As a Bangladeshi, when I claim that I know the Bengali culture, in hindsight I know that I am only familiar with the urban literate middle-class culture of a country where seventy per cent of the people live in rural areas. In fact, as few anthropologists have argued, one cannot conceptualise any society in the current world context - even if the society belongs to the so-called Third World - as having "one system," due to the global flows of various factors such as politics, modern technology, trade, and the mass media (Gupta and Ferguson 1992; Appadurai 1996).

The effects and distribution of the global flows of these various factors are also uneven. In Bangladesh, for example, the global flows of trade or technology may have altered the culture of urban life in many cities, and it is certainly the case that the big cities have experienced more changes than the smaller cities. Additionally, the pace of the global flows is

likely to be slower in the rural villages, due to various social and infrastructural constraints. I have now lived in seven cities (including one in Australia), which have most likely shaped my life and philosophy towards living. Most of my informants, on the other hands, have lived in extreme marginalised social contexts, and none of them had ever travelled to Dhaka, let alone abroad. No one can ignore the differences between my informants and me. Amid these complexities that differentiate both parties, how can I ever possibly claim that I conducted this ethnography at “home”? How can I claim that I was a “native” ethnographer, who explored and provided an “authentic” picture of the villagers?

In earlier times, white Western anthropologists embarked upon their ethnographic expeditions in remote communities, usually in non-Western societies. These scholars contributed to the development of ethnography as a core methodology. But they mostly worked under the influence of friendly colonial rulers. The post-colonial era marked a shift from this classical notion of ethnography with an upsurge of non-Western scholars, who started conducting ethnographies in their own cultures (Hayano 1979). The post-colonial period also saw an emergence of various applied fields in anthropology that also influenced anthropologists to conduct ethnographies on their “home” territories (ibid.). To distinguish these studies at “home”, scholars have used a plethora of terms such as “auto-ethnographer,” “native anthropologist,” “auto-anthropologist,” “indigenous anthropologist,” and “insider-anthropologist.” (Hayano 1979; Messerschmidt 1981; Mascarenhas-Keyes 1987).

Why do we need different labelling for anthropologists who have worked in their own cultures? Citing from Appadurai’s critical observations on the concept of “native,” Narayan (1993) argues that there may have been a perception of “authenticity” at work. According to her, an assumption that a native anthropologist is “an insider who will forward an authentic point of view to the anthropological community” has probably influenced the use of “native” and other labelling for anthropologists working in familiar contexts (Narayan 1993: 676). The

notion of authenticity, Narayan observes, occupies a strong stance in the discipline; simultaneously ignoring how various factors such as education or the “class” of so-called “native” anthropologists, actually dissociate them from their informants. The mixed cultural backgrounds and a variety of other complex factors (education, for example) associated with many prominent anthropologists (such as Lila Abu Lughod) thus undermine the conceptualisation of “native” and the notion of “authenticity” that surrounds the concept (Narayan 1993). Many ethnographers criticise the very idea of authenticity, and call instead for richer narratives with a greater subjective engagement with informants (Clifford and Marcus 1986; Narayan 1993).

The challenges

My personal involvement with my informants also led me to face several challenges during my fieldwork. For instance, among many of my informants, I observed a firm belief that a permanent cure for their illness could be found by visiting urban physicians. Several times they expected me to reveal something new about their illness and how to get a cure. I did not think it would be ethical to be a passive recipient of information for my own interest and give nothing in return. Thus, even though I was not licensed to convey medical information, I told them my personal experience of living with asthma. My responses to the questions about curability varied from one context to another. In cases where the informants were severely distressed and bedridden, I refrained myself from saying that chronic breathlessness was an incurable illness. It appeared to me that the perception of curability was a source of hope (a matter on which I elaborate later in this thesis), something I did not want to take away from them.

There were also other challenges. First, what is research? There is no equivalent term for research in rural Bengali vocabulary. To overcome this difficulty, I used some alternative terms (“survey” for example), which obviously had their own limitations; but they, somewhat,

helped me to explain my purpose. Second, many informants often refused to accept money as reimbursement as they thought it would be “unethical” to accept money just for speaking to someone. Sometimes I would then buy them food or an inhaler. Third, my social status (as someone who was not poor and received education in a foreign country) might have worked as an implicit coercion, influencing villagers to converse with me. In a society that is highly hierarchical and stratified in every sphere of life, how could I possibly engage with the villagers without the pre-established rules of conduct that people would expect to dictate our interactions? In attending this challenge, I tried to give my informants authority through maintaining a verbal passivity on my end, allowing them to take control of the conversation (so that they wouldn’t feel obliged to discuss matters that they did not wish to) and to end our conversations if they did not wish to talk to me. Previous ethnographers have also encountered these challenges when conducting research in rural Bangladesh (see Zaman and Nahar 2011).

Finally, even though I conducted this ethnography in my “own” village, and I was an asthma sufferer myself, it would be unrealistic to claim that I was able to completely comprehend the depth of illness experience that my informants constantly endured. It is quite possible that I missed various aspects of their illness experience due to the multiplicities that are present within the cultural domains and across social groups in a community (Aguilar 1981 in Narayan 1993). Moreover, Kleinman (1995) has noted that illness experiences are far more complex than they appear in the models of anthropology; thus, some aspects of suffering always remain unanalysed in any analysis of distress. Despite the limitations surrounding my inquiry, this study contributes to the small number of ethnographies that explore local experiences of chronic illness in a poor country.

Chapter Three

Being Breathless

Meaning, stigma, and social coping

O Man!

You are just a colourful air balloon (*fanush*),
the sooner the air (*dom*) is finished, the sooner you are gone.³

These two lines are from a popular Bangladeshi folk song. The songwriter uses the metaphor of *fanush*, a type of paper-made air balloon, to indicate the volatility of human life. In a *fanush*, a cloth rag ball soaked in spirit heats up the air inside and makes it alight before the balloon is flown in the sky at night. Historically, the flying of *fanush* has been a common practice in several South Asian cultures, usually to celebrate religious and social festivals. Bengalis living in West Bengal, India, and in Bangladesh fly *fanush* on various occasions, such as during the Bengali New Year's Eve. I have seen my Buddhist friends flying *fanush* to celebrate the moon festival. After a *fanush* is flown, it fades away in the distant sky and drops off soon after the burning cloth lights up the total thing, resulting in the end of the heated air and the end of the whole play. The song here uses the imagery of the dissolution of the *fanush* to convey an idea of human life as something that lasts only as long as the air/breath (*dom*) is inside the person.

Bangladeshis use numerous idioms and metaphors in their everyday conversations about breath. I have heard terms such as soul (*atma*), life (*jibon*), and essence (*pran*) used in an overlapping manner to refer to the critical importance of respiration. I heard the villagers saying, "If one cannot breathe, there is nothing left in life" (*dom nite na parle, jibone ar kichu nai*), which suggests that they attach fundamental importance to respiration. The depth of

³ Singer: Andrew Kishore, Songwriter: Syed Shamsul Haque, My translation

significance associated with breathing means that there would be special attention – be it positive or negative - given to any form of illness that disrupts the regular respiratory process. This means that the people experiencing breathing difficulties often have to devise a variety of socially and culturally acceptable strategies to minimise unwanted attention generated by their condition. I observed one such strategy – that I shall call re-narrativisation – among my informants as they attempted to mitigate the negative societal perceptions associated with chronic breathlessness.

The discussion in this chapter contains three sections. First, I present some social connotations that my informants alluded to in talking about breathlessness. Second, I present some stories relayed to me by my informants. These stories serve to illustrate the common stigmas associated with chronic breathlessness in rural Bangladesh. Finally, I elaborate on the strategy of re-narrativisation, mentioned above, and examine the extent to which this strategy was successful in counteracting stigma.

Meaning

I first met Runa, a woman in her thirties, during a visit to my research assistant Salil's house. I saw her sitting with Salil's mother in the courtyard. Salil's mother invited me to sit on a stool in the yard. I noticed that Runa was speaking in a different dialect, and that her way of wearing sari was a little different from other women in the village. Probably because I was unknown to her, she constantly tried to position her veil correctly, a practice locally considered to be associated with morality and respect. She also wore a pair of *shakha*, a type of bangle made from white shell, and a dot of red vermilion in the middle of her forehead, the two most common symbols distinguishing a married Hindu woman in the area.

She was originally from an adjacent district, which was probably why she spoke a different dialect. She had recently married a man in Jalshiri village, and lived with her

husband in Netrakona district town and occasionally visited the village home. When I introduced myself and briefly explained my research and purpose for living in the village, she seemed intrigued. Since I was investigating lay conceptions of breathing and breathlessness, I encouraged her to share her thoughts on the subject. She described breathlessness as “the most dangerous illness of all.” She also mentioned that it was impossible to “trust the person” who suffered from breathlessness as their *dom* (breath) could be “finished” anytime.

In order to illustrate her point, she told me of an incident she experienced as a college student living in her district town. At the time, she was living on the ground floor of a girls’ hostel on the college premises, where she shared a room with four other girls. One evening, she heard loud shouting in the corridor and saw several girls screaming and running around frantically. She heard, “Nourin is gone! Nourin is gone!” Though Runa did not know who Nourin was, she left her room to investigate. She heard from the other girls that Nourin, who lived upstairs, was unable to breathe. Along with other roommates Runa ran upstairs to the girl’s room where she saw something she struggled to describe in words.

According to Runa, the scene in Nourin’s room was one of the most frightening sights she had ever encountered in her life. Nourin’s anxious roommates, along with some other girls, were gathered together. The room was filled with the sound of constant screaming, intermittently punctuated by desperate suggestions as the girls tried to figure out what to do. Nourin was unable to sit upright continuously, and her mouth was wide open as she struggled to breathe. Her desperate attempts to inhale air, together with the fearful wheezing sound that came from her throat, made everyone in the room extremely alarmed. The girls tried to make her lie down, but it was as though an invisible force was prompting her to sit up. Nourin became increasingly agitated while the girls kept shouting, “Give her the pump [inhaler]...give her the pump. She will be okay if we can give her the gas [inhaler].” Everyone started to panic because her roommates could not hold the inhaler steadily onto her lips. Her

constant movement spread the puffs from the inhaler everywhere, meaning that not much went into her mouth.

Unable to cope with her condition, her roommates decided to take her to the hospital. However, another obstacle emerged that delayed this course of action. The hostel gateman had already locked the main gate, as was his daily duty at 6:00 pm. Once the gate was locked, the guard was not permitted to open it without first gaining permission from the hostel superintendent. This rule had been put in place to ensure the security of the girls and to protect them from any unforeseen circumstances that intruders might create. In fact, most of girls' hostels in the country had their gates closed at a certain time in the evening. Special permission had to be obtained to enter and exit after that time. One of the girls called the superintendent on her mobile phone and requested her to come to the hostel. The delay in the arrival of the superintendent further escalated the girls' anxiety. Some said, "If madam (the superintendent) comes late, we will not be able to save Nourin." Finally, the superintendent arrived, and Nourin was taken to the hospital.

Runa told me that she and all of her friends had thought that Nourin might die on the way to the hospital. Later, Runa heard from the girls that she was given *oxygen* (presumably a nebulizer) on arrival at the hospital. Two days later, when Nourin returned to the hostel, everyone went to see her. For several days, the girls talked incessantly about future attacks of breathlessness that might strike Nourin. Within a few weeks, she left the hostel permanently. Speaking of Nourin's future, Runa mused, "You know, anytime an accident (death) can happen to this type of people, their *dom* (breath) can be finished anytime."

Another informant, Sahajadi, initially attributed her illness to work of processing crops mixed with sludge during the harvesting period. As an elderly woman who suffered from breathing difficulty for more than thirty years, Sahajadi suspected that working in cold and dusty places might have weakened her lungs, and gradually resulted in breathing difficulties.

Although she had a great deal of uncertainty about what may have caused her illness, she had noticed a few consistencies in her experience of wheezing: first, that her illness became particularly unbearable at certain times of the month; and second, that her breathing difficulties were at their worst during the nights of the full moon and new moon. On these nights, the frequency and severity in her wheezing increased to the extent that she needed to drink almost a full bottle of the syrup that her practitioner suggested. She said:

On the nights of full/new moon, my wheezing becomes so severe that I become fidgety and restless. I cannot talk. If you see me you would think as if I am suffering from epilepsy. I feel (someone) is pulling the air out of me. When it starts, I feel like my chest trembles. My legs and hands start twinging. To save life I hurriedly rush and drink Butol. I drink it and sit quietly somewhere. My daughter starts blowing air with *pankha* (a hand fan made of coconut leaves) and I do not go out (on these nights).

More than half of the informants linked the exacerbation of their breathlessness with the order of the lunar cycle. My mind, habituated to searching for material logic, began to search for some scientific reason to explain this phenomenon. I wondered whether it was in fact the cool weather. Or maybe just a notion lodged “in the villagers’ heads” that led them to believe their breathlessness increased in tandem with the moon cycle. Once again, my informants came to rescue me from such narrow thoughts, explaining how the moon cycle affected respiration. Shopon, an elderly man in his eighties, stated that a mother might transmit various illnesses including chronic breathlessness (*hapani*) to her unborn child, especially when changes in the moon occur. According to him, an expectant mother must always be careful of what she is doing and where she is going on particular days of the moon’s cycle. In an attempt to elaborate this theory, he explained:

The human body is closely connected to the cosmic order, especially to the full/new moon. During the nights of the full/new moon, there will be changes in the river. There will be either high tide or low tide (in the river). Why? Because, everything

[around us] is connected.... including our bodily processes. When there is high tide in the river, it will be transmitted in the humans' bodies.

According to Shopon, God created all the things that surround mankind, including the temperature of the weather, the cycle of the moon, and people's bodies. Upon creation, God also ensured an intrinsic relationship between all things. Therefore, the changes in the river water consequently brought changes in the bodily process through air/wind, two other creations of God. The stories of Runa, Sahajadi, and Shopon suggest that the perceptions of breath in rural Bangladesh might be more than just a bodily disturbance.

What is breath? What does it mean to be breathless? Early thinkers invested a considerable amount of thought in their attempts to understand the respiratory process of living animals. Aristotle (1897: 104) wrote, "The entrance of the air is termed inspiration, and its exit is called expiration; and so long as the animal lives, these motions of inspiration and expiration go on without interruption, so that life and respiration are inseparably bound together." This positivistic approach provided some of the key elements still found in the conception of respiration in Western biomedical tradition. Western biomedicine, which is based upon a scientific epistemology, focuses on a physiological understanding of respiration. It tends to consider respiration as "an ideologically neutral sphere of human activity" (Green 2008: 284).

The positivistic concept of respiration concentrates on the biological components of the respiratory system. Two important parts of the respiratory system are the trachea and the bronchi. The trachea is the long tube that carries the inhaled air to the lungs; just before reaching to the lungs, it becomes divided into two small air tubes called bronchi, which allow oxygen to reach both sides of the lungs. Both bronchi later become divided into smaller branches called bronchioles, which finally become "clusters of microscopic air sacs" known as alveoli (Alcamo 2004: 355). Alveoli perform the actual tasks of absorbing oxygen into the

blood and extracting carbon dioxide from the blood. This regular system of airflow becomes affected when individuals suffer from a breathing difficulty. Biomedical diagnoses of an obstruction to the respiratory process are based on biological changes such as shrinking of the airways (ibid.).

From a lay perspective, however, both inhalation and exhalation may appear as the transmission of air instead of the scientific conception of oxygen and carbon dioxide. Many anthropological studies undertaken in Asia, and in other parts of the world, have explored how lay conceptions of respiration go beyond seeing it just as a bodily process. In such contexts, concepts of respiration may traverse a moral and religious world, encompassing concepts of air, wind, spirits, life, and a notion of the vitality of the Universe (Zysk 1993; Hsu 2007). Anthropologists Chris Low and Elisabeth Hsu write of just such multifaceted and overlapping notions of air:

Wind, on first consideration, may be thought of as a ‘natural phenomenon’: ‘air in motion’. Our different words for wind, including breezes, wafts, squalls, whirlwinds, hurricanes, and cyclones, tell us something about the origins, scale, and implications of the phenomenon. Cyclically or erratically winds appear and dissipate across the landscape as one of the primordial rhythms of unfolding life and part of the backdrop of life in the open. Yet wind is also experienced indoors, in the form of ‘drafts’ and ‘currents of air’, and if it is not reduced to a phenomenon of modern meteorology and the natural sciences, wind can also be thought to manifest in breathing and in the internal body winds that circulate in veins or appear in the form of sneezes and coughs. Or winds can be deities and spirits (2008: 1).

Their edited work *Wind, Life, Health* contains several anthropological investigations of how people from various parts of the world observe the overlapping meanings of wind, air, and breath (Hsu and Low 2008). Such overlapping perceptions suggest that it is not uncommon for lay people to understand respiration through distinctive social and cultural meanings.

Similarly, the stories of my informants demonstrate at least two particular local perceptions of chronic breathlessness. First, there was a particular cultural perception of fear and uncertainty and second, there was an explanation of inter-connectedness between the Universe and bodily processes. Runa's story, for instance, ended with a firm expression of the ever-present uncertainty that lingers in the lives of those suffering from chronic breathlessness. What was this uncertainty about? What did Runa mean when she said it was impossible to "trust" people with breathlessness? I do not think she was referring to "trust" in terms of illegitimacy. Rather, it seems likely that she was trying to convey how a person with breathing difficulty could unexpectedly cease living, and that this could happen at any time. For this reason, one could not rely on (trust in) the person's survival capacity.

In the lives of rural Bangladeshis, the reference to death has a particular ethnographic significance. If one looks closely, it was not death per se that caused Runa's apprehension, but rather the fear of *unexpected* death. Jalshiri people regarded "age" as the primary criterion by which to determine whether a person's death was expected or unexpected. However, there were also contradictions in this perception of expectedness in death. If someone was immobile for several years, or bedridden due to a life-threatening illness, it was often said that it was better for the person to die and attain peace, than to remain alive and endure suffering. Yet, when an actual death occurred in the village, it also seemed that every death was considered to be unexpected.

This same principle held true for those suffering from chronic breathlessness. That is, it was not the notion of death that dominated their social interactions; instead, it was a *continual* fear of death. Breathlessness remained "invisible" until the actual symptoms of the illness revealed themselves. During the in-between wheeze-free periods it appeared as if the person did not have the illness at all. But constant worry about the next attack always marred

the peacefulness of these relatively symptom-free periods. In other words, fear of an attack (that could result in death) persisted, irrespective of the condition of the illness.

The second dimension was the notion of inter-connectedness, which should not be seen in terms of a religious perspective only. This explanation was more of a cosmological analysis of existence, rooted in local cultural belief. This cosmological perception, as many ancient texts (such as the Vedas) in the region show, has existed in the region for millennia. The Vedas, the earliest literary record in the Indian sub-continent, have been transmitted orally since ancient times and later compiled into text. Dasgupta has written of the compilation process:

It is indeed difficult to say when the earliest portions of these compositions came into existence. Many shrewd guesses have been offered, but none of them can be proved to be incontestably true. Max Müller supposed the date to be 1200 B.C., Haug 2400 B.C. and Bal Gangadhar Tilak 4000 B.C... (1922: 10)

As an authoritative text, the Vedas have had a profound impact on the thought and practices of Indian philosophical, cultural and also administrative traditions. The discussion of bodily winds in the Vedas is of particular relevance to the discourses of rural people even today. When I carefully examine the various vocabularies that my informants used, I find a common presence of the Bengali word *pran*. An approximate translation of *pran* in English could be “life”. But the Bengali word *pran* is more closely a derivative of the Sanskrit *prana*, one of the important bodily winds discussed in the Vedas. The *Samsad Bengali-English Dictionary* provides various definitions of the Bengali word *pran*. Each of these glossaries refer interchangeably to “life” and to “the first of the five vital airs”, or “life-breath.” In fact, there is virtually no difference between this range of meanings of *pran* and the meanings of *prana* described in the Vedas.

Five bodily winds (*prana*, *udana*, *samana*, *apana*, and *vyana*) are described in the Vedas (Zysk 1993; Zysk 2007). Ancient Indians wanted to understand bodily processes through the concepts of those bodily winds (Zysk 1993). Zysk wrote,

1. Prana, the “front breath,” located in the mouth, ensures respiration and swallowing; 2. Udana, the “upward moving breath,” produces speech; 3. Samana, the “concentrated breath,” promotes digestion; 4. Apana, the “downward moving breath,” ensures excretion and childbirth; and 5. vyana, the “diffused breath,” circulates in the limbs and motivates their movement. (1993: 201).

Of all the bodily winds, *prana* received particular attention as it was seen as “the vital breath,” or “the principal wind” (Zysk 2007). The Vedas described three forms of *prana*; they were life, wind (*vata*, *vayu*), and the respiratory process. The ancient Indians saw the presence of *prana* (breath) in living things as “the principal indicator of life”: they also observed life to have ceased when it was absent. Similarly, they observed “wind” as something that represented life in living things. They also observed the same phenomenon in nature. Thus, wind/breath have been given different names, so as to distinguish the various forces: *vayu* (wind) in nature, and *prana* (breath) in living things (Zysk 2007).

In addition to life and the promotion of longevity, the Vedas also referred to *prana* as seeing, hearing, and the strength of life. *Prana* was “the vital factor” that controlled the Universe: it was lord of all things in the cosmos, irrespective of whether they breathed or not. The Vedas also referred *Prana* as the cosmic wind (air) that blew in the atmosphere and animated and regulated the normal course of things and maintained the cosmic order. The wind (*vayu*), another manifestation of *prana*, represented the breath (*prana*) of humans, the cosmic person (Zysk 1993; Zysk 2007; Zysk 2008).

The discussion of bodily winds left a longstanding impact on several aspects of South Asian cultures. After ancient Indians realised the critical importance of *prana* in living things, they attempted to nurture and cultivate it regularly. This practice later contributed to two

streams: first an ascetic practice of breath-control in the practice of Yoga, and second, its influence on the practice of Ayurved (Zysk 2007). In their attempts to gain knowledge about breath, the ancient Indians started practicing *pranayama* or breath-control, which involved inhaling, exhaling, and retaining the breath. This type of arresting or controlling breath later appeared as the central aspect of the tradition of Yoga. But, with the passage of time, Yoga became practiced not just as a breath-control technique “but also [as] a meditative process whose aim was the mind’s stabilisation and fixation on a part or parts inside the body” (Zysk 2007: 108). The ongoing practice of focusing on body parts through concentrating on the movement of air later resulted in a medical tradition. Over a long period of time, the concept of bodily winds was refined, and came to be thought of in terms of physiological and anatomical functions and locations (Zysk 2007). Medical authors of the era adopted these concepts as “norms” in the epistemologies of Ayurvedic medicine (Zysk 2007: 108).

At present, both Yoga and Ayurved are parts of the contemporary lives of the people in South Asia. Indeed, this “ancient” conceptualisation of bodily winds is still relevant in the contemporary socio-cultural practices of the region. In this discussion, it is crucial to note that the term “Indian” does not necessarily refer to the peoples of the nation-state India. Rather, the term here refers to the people of an earlier regional field that comprised an area known as the Indian sub-continent. One may also ask how far the notion of bodily winds – something that is essentially derived from a Hindu tradition – is applicable to the perceptions of respiration in Bangladesh, a country that is predominantly Muslim? My analysis in this regard is by no means an attempt to reach to an exhaustive generalisation. Addressing this question requires revisiting the particular cultural history of Bangladesh to see how junctures of culture and religion have played – and continue to play – critical roles in various spheres of people’s lives.

Current Bangladesh and West Bengal province of India used to be parts of a previously unified territorial category, “the Bengal.” In the past, people of the Bengal were followers of Hinduism or Buddhism. Some claim that the initiation of Islam in the Bengal occurred in eighth century (Huque and Akhter 1987) while others believe that the advent of Turkish and Arabic Muslims in the beginning of thirteenth century created a context of Islamisation in the area (Karim 2006). The Muslim conquerors occupied the Bengal region for five hundred years, and the Islamisation process received momentum through the establishment of numerous mosques and *madrasas* (religious schools) (Huque and Akhter 1987). Many low-caste Hindus responded to the call of Islam, as it offered an escape from the rigid, hierarchical caste system of Hindu society, while simultaneously providing an accessible path to salvation and success (Hartmann and Boyce 1983: 214-227; Karim 2006). The progress of Islam was uneven. Some areas (Bangladesh, for example) widely accepted the religion, whereas in the other areas (the West Bengal, India for example) Islam was not as widely accepted. Consequently, the expansion of Islam occurred over a period of time, in a region that was historically dominated by Hinduism.

A notable aspect of the Islamisation process in the Indian sub-continent was its particular form. Islam in the sub-continent was somewhat different to the Islam of the Middle East or indeed of many other Muslim countries (Sarkar 1972; Roy 1983; Eaton 1993; Chowdhury 2011). Both Islam and Hinduism adopted various components of one another’s religious practices. This was likely due to the fact that the people of Bengal shared much in terms of language, food, livelihood and many other cultural components. Consequently, there was a blurring of local Islamic and Hindu religious practices among Bengali people, irrespective of their location or religious beliefs. The prominent historian Asim Roy (1983) has observed these various idiosyncrasies of Islam, including the cults of Sufi *pirs*, and employs the term “syncretistic” to refer to the Islam in Bengal. Others, such as Hartmann and

Boyce (1983) have also acknowledged the blurring of boundaries among religions in the region. In speaking of Bengal, they use the term “the hybrid culture”, and describe Hinduism and Islam as being “like two curries spread on a plate of rice – it is impossible for them not to blend together” (Ibid.: 214). Anthropologists have also observed this syncretic nature of Islam in Bangladeshi society (see, for example, Blanchet 1984). As such, when my informants referred to the notion of inter-connectedness between the lunar cycle and an exacerbation of breathlessness, their explanation did not reflect a formal religious doctrine. There was no distinction between Hindu and Muslim informants in terms of their explanations in this regard. It would be more accurate to describe their understanding of this phenomenon of breathlessness as a juncture of cultural, religious, and cosmological perspectives. It is highly likely that my informants’ analytical perspective on a notion of “inter-connectedness” was a cultural derivative of the cosmological explanations of *prana* in the Vedas.

Similar to the way *prana* explains the relationships between wind, breath, and the Universe, *pran* in Bengali also carries such expansive connotations. The Hindu villagers of Jalshiri, for example, worshipped the god of the winds (*pavan*), another term for wind that refers to its inhibition in the atmosphere. As the ruler of the atmosphere, the god *vayu* (wind) is able to control the wind in natural world, and also to control the wind that takes the form of the vital breath (*prana*) in living things (Wilkins 2003). Based on these observations of the use of the same conceptual terms, the rituals of worship, and the discourses around breathlessness and lunar cycles, I conclude that the rural villagers understood respiration as a cultural derivative of the conception of bodily winds in ancient India, which carried a cosmological dimension linking body and the Universe.

In order to further understand the local meanings of breathlessness, we need to examine the use of the concepts of *dom* (breath) and its relationship with *pran* (life) among the people of Jalshiri. While expressing the fear of sudden death, Runa stated that breath (*dom*)

of the individuals with chronic breathlessness could be “finished” at any time. The English translation “breath” for the Bengali *dom* is probably a poor - albeit not entirely incorrect - translation due to the complexities involved with the concept of *dom*. When we use the English word “breath,” we usually do not refer to something that can be “gone” or be “over.” However, the villagers of Jalshiri often used *dom* as an everyday idiom when speaking about multiple aspects of their daily lives. For example, they might use it when referring to a dying animal, saying that its *dom* was about to “leave” the body. In this sense, *dom* coincides with the concept of spirit. Similarly, they may also try to give some drops of water down the dying animal’s throat in an attempt to help restore its *dom*. The villagers often spoke of *dom* as “the central thing” of all activities of life; they would say that all efforts to gain extensive wealth amount to “nothing”, as when the *dom* ceases, all possessions have to be left behind. On the other hand, *Dom* was not described as something that could be quantified or stored, as if in a reservoir. So, if *dom* was not seen as something stored in a certain amount, how could it be “finished”? In order to explain this, the villagers suggested that God produced *dom* inside the human beings and nurtured life (*pran*), the focal point of everything. Instead of referring to *dom* being stored in a certain amount, the villagers used the local colloquial term “finish” to indicate the incidence of when *dom* ceases to exist and threatens life (*pran*). The life (*pran*) faced a real danger in the case of chronic breathlessness. It simultaneously posed a threat to the sufferers rendering them “untrustworthy” in relation to their ability to live.

Based on these premises, it is clear that for rural Bangladeshis, the experience of chronic breathlessness goes well beyond just an experience of physiological disturbance. Rather, it occupies a central position of socio-cultural and cosmological significance. Understanding chronic breathlessness in this way explains the strong reactions of people in Jalshiri towards individuals who suffered from breathlessness, as these reactions stigmatise and enhance the suffering of individuals living with chronic breathlessness.

Stigma

One day I was speaking to a middle-aged man about the incidence of chronic breathlessness in the village. The discussion slowly wove its way to the social aspects of the illness. At one point, he told me:

If people know that a young boy like you [pointing at me, the researcher]...please don't mind, I am just giving an example, have *ezma* [asthma], no family would allow you to marry their daughter. They would think... 'who knows what would happen... he might die anytime...' There will always be a suspicion about you [and your capacity to survive].

Given the strong stigma associated with the illness, and having used me as an example, the villager apologised immediately in case I was offended. Nevertheless, this discussion reminded me of my own marriage. Although my mother tried not to tell people about my asthma, I often revealed this myself. My mother feared that I might face stigma due to all the rumours that would spread through people's voice (see Das and Addlakha 2001: 514). However, the reason my asthma did not hamper my marriage prospects probably has a lot to do with the cultural capital (see Bourdieu 2002) I have acquired by studying and living in a foreign country, something that was not possible for most of my informants. The fear of an unexpected death that surrounded individuals with chronic breathlessness had the potential to negatively affect a wide range of aspects of their lives, and this was poignantly demonstrated through their marital arrangements. The villagers exercised caution when there was a prospective marriage proposal. Many often went to great lengths, even spying, in order to obtain information about a person who was considering getting married. The self-taught medical practitioners (see Chapter 6) in the village bazaar often served as a go-between for such endeavours. One practitioner, Ali, told me how one groom-to-be slyly attempted to investigate whether his bride-to-be had chronic breathlessness (*hapani*). He told me about a young man who came to see him to inquire about a girl he was about to marry. Ali described:

...one day, a young man came and asked me what sort of illnesses I usually treat. Then he starts talking about one particular family in the village. At some point, he asked some specific questions about a daughter in the family. Why would a young man enquire about a young marital-aged girl? It must be about wedding. He was probably thinking to get married to that girl, or he came to collect information for someone else. Initially, he asks me if I have treatments for sexual diseases, tuberculosis etc. Then he goes asking what sort of medicines that the family members usually get from me. He told me that he saw some cold syrup on the table of that family. [Then he asked] Does anyone in the family have breathlessness? Does that girl have breathing problem? I do not support this. Based on my one comment, the wedding of a girl would come to a halt, it should not happen. I cannot ruin someone's life...I did not give any information. I told him that the family has only normal cold problem and that is why he saw the cough syrups. It is a matter of life of a girl, you know. I cannot destroy her life. I did not give any information even though I knew she had chronic breathlessness (*hapani*).

Later, Ali explained why the groom-to-be made an attempt to spy about the girl he wanted to marry:

In terms of illness such as chronic breathing problems, people want to be cautious; they want to be picky (*ektu baicha colte chay*) about wedding types of things... People usually think if a mother has this illness, her son or daughter might get that (illness) too. The future groom might think, "Why would I sufferby marrying such an ill girl?"

Ali's opinion shows that the decision on a prospective marriage in Jalshiri involves considerations to various aspects, in particular to illness like chronic breathlessness. Further, despite the great caution that was exercised in choosing prospective partners, sometimes the illness was discovered after the marriage had taken place.

When a "defective" partner was discovered after marriage, there were overarching emotional effects for both partners. This happened to one of my informants, Sumon, who told me he felt "deceived" when his wife's breathlessness was revealed after their marriage. Sumon was a thirty-five-year old man who owned a clothing store in the village bazaar. He was a father of two sons, the younger of which had suffered from physical and mental disability since birth. Sumon told me that his cousin had arranged the marriage with her

(cousin's) sister-in-law. His parents and other relatives had gone to his parents-in-law's house to arrange the wedding, and Sumon had never seen his wife before the wedding day. His family had relied upon the cousin to make a sound decision regarding his marriage.

A couple of months after the wedding, Sumon was shocked to discover that his wife, Seema, had a wheezing problem. Initially, he thought it was just a temporary cold-related wheeze. But, when his wife became bedridden for several days at a time, especially during the winter season, he soon suspected the illness was *hapani* (chronic breathlessness). He purchased some medication in the village bazaar to try to treat her condition. When she did not improve, he took her to the city for treatment, but this also failed to cure her illness. And so Sumon stopped taking his wife to the city doctors, opting to purchase her medication from the village practitioners instead.

Seema's illness greatly affected the family. On days when she was sick and bedridden, she could not perform any household work, let alone care for her elderly parents-in-law. Sumon expressed his frustration to me, saying that he often had to do "female tasks" such as cooking during these times. He also had to care for his disabled son who was not able to eat by himself, and always needed someone to help him. Sumon also suspected that his son's disability probably had something to do with his wife's breathlessness. Because of her breathlessness, he told me, she was "probably not capable of producing a healthy child." I found this argument unconvincing, as his other child was healthy. While talking about his wife's illness and the household works that he had to perform, Sumon displayed extreme anger. He told me that he often cried and mourned his fate. He expressed great frustration that he had let his cousin (who he referred to as his sister) arrange his marriage. He was furious with his sister, saying to me, "How could she ruin my life?" He could not believe that his

“own sister”⁴ had gone ahead and arranged the marriage when she knew of Seema’s breathlessness. He felt that his cousin and her husband wanted to hide the information of the illness because they knew that Sumon would not marry a girl with chronic breathlessness. According to Sumon, they just wanted to get rid of the woman by arranging this wedding. Since discovering his wife’s illness, Sumon stopped visiting his cousin’s house. He clearly felt that his cousin had tricked him and this had caused a serious deterioration in their relationship.

In a patriarchal and patrilineal society such as Bangladesh, the suffering of women often remains passive or unheard. Previously anthropological investigations have explored the ways many factors such as “dark” skin or the presence of a genetic disorder affect the marriageability of Bangladeshi women (Rozario 2002b; Rozario 2007; Rozario 2013). While listening to Sumon, I could not even begin to imagine the extent of the devastation that his wife had to endure every day, and especially on days when she could not perform her household work due to her breathlessness. I was not able to speak to his wife without Sumon and his parents being present. But I heard from some of their neighbours that she often locked herself in a room and cried when her husband blamed her, saying that he was tricked into marrying her. I am sure if I could have spoken to her separately, I would have been able to explore her experience more deeply. I was, however, able to gain access to the experiences of a few other women sufferers more deeply. The next section explains the stories of Sahara and Julekha, two women who faced social and familial exclusion as a result of their illness.

Sahara

Sahara was a sixty-year old woman who had been suffering from chronic breathlessness for the past ten years. After I met Sahara’s daughter Zamila, I realised how

⁴ In Bengali Hindu culture, cousins are seen as close to siblings. For example, my aunt’s daughter would be close to my sibling sister.

stigma surrounding breathlessness, when coupled with severe poverty, can increase person's suffering considerably. Zamila was thirty years of age and married; she was the only daughter of Sahara. Her family consisted of Saiful (her husband), her son, and her elderly mother Sahara. Elderly parents in Bangladeshi society usually live with their sons and in most cases with the eldest son. And, while society expects the eldest son to take care of his elderly parents until they pass on, similar societal expectations from a daughter are rare. When I learned that Sahara was living with her daughter Zamila, it immediately struck me as unusual. Because of this "transmittable illness" (*bodla rog*), as Zamila stated, her brothers refused to take care of Sahara. I later discovered why Zamila was "willing" to take care of Sahara whereas her brothers had refused to do so.

I went to meet Sahara after I heard about her breathing difficulties from other villagers. The house was in a small section of the village known as Sheikhpara, predominantly populated by Muslim villagers. Like most of the houses in the village, her house smelled of cow dung. Cow dung paste was used to paint the houses and it was considered to be a form of cleanliness. The house also had a tin roof – another common feature of village houses – tin being a cheap building material commonly used by villagers. The walls were made from bamboo strips, their surfaces coated with mud and cow dung paste. The house had been built as a one-bedroom dwelling, and later a fence of bamboo strips was erected, creating two sections. Houses of this kind are susceptible to damage, which can happen quickly with only a little rain. The fragility of the house was probably a representation of the acute poverty that the family lived with.

The site upon which the house was originally built belonged to Sahara's husband. When her husband died, Sahara had been left alone in her house, and so she was happy to have her daughter and son-in-law living with her at present. Zamila and her husband's "willingness" to take care of Sahara revolved, in fact, around the fact that their own house,

located next to the river, was washed away during a flood. Zamila's husband, Saiful, used to work as a yearly hired labourer on people's farmlands, but he lost his job within a few years of his wedding. It was hard for him to rent a house as he was only a daily labourer. Within a few years of moving to Sahara's house, Saiful saved some money and put a new tin roof on the house. It was not long before Saiful and Zamila began to fight over whether they should continue to take care of Sahara. Saiful did not like his mother-in-law staying with them. He repeatedly emphasised that it was not their duty to take care of her elderly mother. During these arguments, Saiful had even physically abused Zamila a few times.

To some extent, Zamila agreed with her husband that the first responsibility to care for her mother lay with her brothers. So, even though Sahara had provided her home for them, their investment in rebuilding the house together with societal expectations that they were not responsible for Sahara's care, led them to consider her a burden on their family. Inevitably, this formed the subject of daily quarrels between Zamila and Saiful. As Zamila told me:

If I buy medicines for my mother, he would scold at me. He would often become furious. He beats me. He tells me, "Where do you get money to buy medicines for your mother. You definitely use [the money] I give you to run the family." I tell him that my brothers sent money to buy medicines for her. He asks, "Several festivals go by... [like] Eid and others... I never see your brothers giving anything to your mother, how come they give now." It is true... I try to hide some money from the family expense so that I can buy the medicines for my mother... I can't watch my mother struggling to breathe...I can't hold my tears.

Their frequent quarrels were further exacerbated by the negative social attitudes toward breathlessness. Saiful would often say to Zamila, "Your brothers do not care for your mother because they do not want to die [of breathlessness]." In support of her husband, Zamila stated that *taner dosh* (chronic breathlessness) and *daud* (a type of skin disease) were similar illnesses inasmuch as they could both be transmitted from one person to another. She said,

Her [Sahara's] plate and glass are kept separate. I don't mix her plate with ours. I wash them separately and keep [them] far away from where we keep ours. I gave her a separate *kolsi* (a local water storage pot). I pour her *kolsi* from the tube-well and put it next to her bed. She drinks her water from that *kolsi*. What can I do? These diseases are transmittable [*bodla*]. If someone has *daud* or *taner dosh*, anyone who is nearer might get the illness.

Zamila added that if her mother did not have this illness, there would be less household work for her. Twice a day she had to walk to the end of the village to get drinking water. She would bring water for the whole family and later pour some into her mother's *kolsi*. And, because the kitchen utensils had to be kept separate, every time she would have to go to the pond twice to wash them separately. All of this extra work made her very tired by the end of the day. In addition, she was extremely worried about her only son who always wanted to sleep with his grandmother. Even though she tried to stop him, she was not always able to do so. She was scared that in future her son might develop his grandmother's breathing difficulties. In this regard, Sahara shared her daughter's sentiment, and was also afraid for her grandson.

On our first meeting, elderly Sahara appeared weak and clearly unwilling to talk to me. Upon seeing me, Sahara raised her eyebrows, a gesture signifying questioning in Bangladeshi culture. Locally, the gesture was also an expression of disturbance and occasionally, of anger, depending on the mode of conversation. Instead of asking about her illness, I initiated a discussion about her family members. She was quite happy to talk about her sons who lived in Dhaka. She had once lived with one of her sons in Dhaka but returned before too long. She was not treated properly by her daughter-in-law. She never had breakfast until twelve o'clock as the daughter-in-law did not invite her to eat. Sahara had chewed *paan* (a kind of smokeless tobacco) since she was fifteen, but her daughter-in-law did not like her chewing *paan* in the apartment so she asked her to stop. She was only able to see her son at night and this made her

even more distressed. She cried every day. On her return from Dhaka her breathing difficulties increased enormously.

Expressing her anxiety about her grandson, she asked me whether breathlessness was “truly a transmittable illness.” Her grief about not being able to spend enough time with her grandson, despite staying close to him, was deep. Culturally, in Bangladesh, the relationship between grandparents and their grandchildren is both fond and a source of mutual amusement. The grandchildren usually spend a considerable amount of time with their grandparents, more than they spend with their parents. The father is usually busy working outside and the mother engaged in household chores; so, the grandchildren spend most of their time with their grandparents. In this particular case, this culturally-approved time between grandparents and grandchildren had become highly contested because of Sahara’s breathlessness. Sahara had to keep trying “not to mix with him too much”. At some point in our discussion, she wiped away some tears. She became more distressed when she talked of how she felt excluded when interacting with other villagers:

[After] people know about this illness [of mine], they don’t want to come closer to me (*Onno keu janle, amar dhare virte chayna*). They keep a distance from me. They fear the illness will attack them too. People don’t even want to drink water if they come to our house.

Julekha

Julekha, a thirty-six-year old woman and mother of two sons and two daughters, also expressed enormous distress regarding the way her young sons treated her. Even though she felt weak all the time, she could not afford to stay home. She had to work. Her husband’s income was too small to feed a family of six. I met Julekha at her workplace which was one of the digging sites run by Concern Bangladesh, the local branch of the International NGO Concern Worldwide.

Concern was running several projects involving the digging of canals in the area. The organisation mainly employed poor women in these digging canals projects. As flooding was inevitable in the region, and occurred on an annual basis, a strip of sandy land rose out of the river bed and closed the waterways for boats during the winter season. Concern's canal digging projects worked as an alternative mode of flood management in the area. While some villagers suggested that the organisation's projects were insufficient to control the flooding, they nevertheless created employment opportunities for local women like Julekha, who greatly appreciated the opportunity to earn money.

However, some affluent housewives expressed their frustration with Concern, claiming that these kinds of projects sharply reduced the number of women willing to work as housemaids. They were right, insofar as most of the women who previously worked as maids for wealthier villagers preferred to work in the Concern's project, and there were only a few women left willing to work as maids. The well-off housewives, who previously hired more than one maid, were annoyed that now they had to struggle to find even one during periods when the digging projects took place. Concern paid higher wages and the hours of work were fewer compared to the wages and hours of work as a household maid in the area. At the same time, some women who worked on Concern's digging sites expressed the discomfort they felt working outside with unknown men. Many among them, nevertheless, were happy to be paid 150 taka (approximately \$2)⁵ for six hours of digging work per day. This picture of women working outside their own home in paid employment rather than as maids at rich people's houses is a relatively recent trend in the lives of rural Bangladeshis, and is connected with several economic interventions made by government and non-government organisations (Rozario 1997; Rozario 2002a; Rozario 2006).

⁵ 1 AUD =70 Taka (August 2012)

When I saw Julekha at a digging site next to the bridge that connected the village with the bazaar over the river, she was shovelling soil into a basket. Once the basket was full, I watched as she carried the basket on her head to a half-made muddy road where she dumped the soil. The soil was being used to construct a muddy road between the riverbank and the village.



Picture 4: Work at a digging site

When we first met, Julekha thought that I was a physician studying breathlessness in Australia. She was very excited to have a “foreign doctor” who she could ask for some “effective medicines that would make the illness go away”. After I explained my research, she was clearly disappointed. She said that many people like me visit the village, ask about family members, and undertake many *jorip* (surveys); but in the end, they are of no use. Although she did not see the value of this kind of work, she was nonetheless willing to talk to me about her own illness experience.



Picture 5: Resting at work

She was particularly frustrated by the way she was treated by her sons. She was doing hard work like digging soil, and suffering the cultural shame associated with working with men, in order to help the family. She became particularly distressed when she recalled her son telling her to be “careful.” She said,

[Lets] leave aside other villagers, they, of course, see me negatively, that is usual. But my own son says, “Amma, don’t you use our glasses and plates. It is frightening to see how you breathe. You must use a different glass to drink water. We will not drink or eat anything you serve. You breathe like Rubel’s mother. Rubel’s mother has this bad illness. You probably got the same illness. We will not drink water from your hand.

As she spoke to me, Julekha began crying out loud. Her tears and grief clearly touched the other women on the digging site. Hearing her cry, some nearby women came to console her. Julekha’s wailing continued: “Allah should take me from this earth. My own son hates me because of this illness.” Listening to her, I felt really sad. I sat there for a while, unsure

what to do. Even though she was my elder, I could not comfort her more closely because of the societal disapproval of such interactions between a man and a woman, especially in public spheres (see Rozario 1992). I sat next to her and tried to console her saying: “Sister, don’t cry. Everything will be fine”. I did not know what else to do. I felt sad for her. After she regained her composure, I asked her to accept one hundred taka because she had kindly talked to me while she was at work. She strongly rejected the money protesting that it would be unethical for her to take it as she “did not do anything.” She finally accepted the money, but only after my repeated requests and reassurances that I would be reimbursed by my university.

In Julekha’s story, we see how powerfully the societal attitudes attached to breathlessness negatively impact the lives of sufferers. The perception of sudden death and the suspicion surrounding whether the illness was contagious, or hereditary, played particularly critical roles in the development of stigma. Despite the presence of a great deal of ambiguity and uncertainty in these societal perceptions, sufferers nevertheless faced enormous social stigma.

Social coping: Counteracting stigma with narrative

In the course of my fieldwork, I noticed that the local terms for breathlessness carried extremely negative connotations. These negative connotations, in turn, greatly affected the sufferers’ conversations with me about their illness. Take for example, Apu, a 32-year-old businessman, who was diagnosed with tuberculosis in 2000 and cured after six months of treatment. His breathlessness began during his treatment for tuberculosis, as he described for me during our interview:

..After I had taken the [tuberculosis] medicine for five days I had to go to Rangpur for business. At that time I suddenly fell sick. I had [his voice becomes low and hesitant and then trails off in silence]...I started to suffer from this [he speaks in a low voice, and avoids using any specific word for it]... [pause] breathing difficulties [spoken in a very low voice]... I could

not exhale properly. After some time it became alright by itself [his tone returns to normal]. But I got scared; I took the bus next day and came back. After returning home, the same thing happened 1-2 days later. My brother took me to the hospital. They gave me medicines for my *shashe somossa* (problem of breath)... I think my breathing problem happened because of the *tibi* (tuberculosis) [spoken in a low and sad voice]. I never had any problem with my breathing before [now speaking emphatically].

This excerpt was notable for the changes in the tone of Apu's voice, indicating his shame and perceived vulnerability to breathlessness. Even though tuberculosis is also a strongly stigmatised illness in Bangladeshi society (Karim, et al. 2007), his tone and expressions were unremarkable when he alluded to tuberculosis, perhaps because the disease was no longer active in his body. But there were considerable fluctuations of tone and expression when he spoke of his breathlessness. Moreover, he never used the Bengali term *hapani* when talking about his breathing difficulty. He either used *shashe somossa* (problem of breath) or tended to avoid explicitly mentioning the illness.

This strategic avoidance of stigmatised terminologies was also present in my discussions with other informants. Roni's expression of his breathlessness, for example, took a similar path. I turn now to his example. Roni was a 24 year-old man who worked in a photographic studio. After a villager told me about his *taner dosh* (chronic breathlessness), I went to meet him in his studio at the bazaar. Although the studio was not big, it had a small section at the front with a glass door. Some posters of famous Indian and Bangladeshi actresses had been attached to the glass to attract prospective clients. My initial attempt to interview Roni was unsuccessful, despite the fact that we had a good conversation. When Roni heard that I was a student in Australia, he expressed a keen interest in my Australian life. He knew drinking alcohol was not illegal in *bidesh* (foreign countries) and so asked me if I drank beer in Australia. He said that if he got a chance to visit Australia, he would drink beer for a month. I told him about the social and collegial aspect of drinking in Australia. I told him that not everyone in Australia is drunk all the time, or swimming in alcohol, even though

the consumption of alcohol is legal. Later he also asked me about how women in Australia dressed and whether they were sexually “forward”. He asked me if it was true that they did not care about their own families. I was not surprised by his comments about Australian women being sexually forward as I had heard these comments a few times before. I was even asked whether I had engaged in sex with numerous women in Australia.

When I told Roni that Australian women were not less caring towards their families than Bangladeshi women, he stared at me with great disbelief. He referred to English movies (Hollywood movies) he had seen to defend his views. But finally he had to accept my opinion as I was living in Australia. At some point in our discussion, he called me *dosto*, a term mainly used among close friends in local culture. I tried to orient the discussion towards my research topic but his enthusiasm for our discussion and the camaraderie that had been developing between us quickly faded. After some time, he reluctantly expressed his opinion, saying that breathlessness was on the rise due to the everyday pollution. Since that first meeting, I saw him a few times in the village bazaar, and although he always smiled at me, he never showed any enthusiasm for engaging in conversation. It seemed to me that he was trying to avoid me.

However, a few weeks later, as I passed his studio one morning, he waved his hand, beckoning me. When I moved closer, he invited me to have a cup of tea with him. This time he took me into a small room behind a glass wall inside his studio. As I passed through the reception area, a big poster featuring Aishwarya Rai, an Indian actress and one of the winners of the world beauty pageant, welcomed me in a typical Indian style, her two hands clasped together palm to palm. *Wellcome* was written beneath the poster. At the end of the room, there was a small door leading to a tiny area approximately one and half metres in length and half a metre wide. Here Roni kept a desktop computer and printer on a desk. Usually outsiders were not invited into this area. But on this occasion, he invited me to sit there and asked me how I

was going with my research. As our conversation progressed, he seemed keen to hear a success story about a patient who was permanently cured from breathlessness. Later, the discussion moved on to other topics, taking the form of simply chatting. At some point he said,

If I go and sleep in a cool bed, or if I sleep without a blanket, I catch cold. My breathing gets blocked. My stomach becomes bloated. And this [blocked breathing] becomes severe. Also, if I am in a blocked room, you know if the windows and doors are not opened for a few days... or if I am in a dirty place, I get this [breathlessness]. During the summer, I sweat a lot and if my sweat dries on my body, I get cold and I get this problem [breathlessness]. Especially this creates a problem at night when the cough becomes unbearable.

He signalled the illness by saying that his “breathing gets blocked”. Later when describing an experience of wheezing, he changed his use of “this illness” to “*shashe somossa*”:

I was up all night for *shashe somossa* [problem of breath]. I could not sleep. I sat in front of the television and spent the whole night there. At dawn, I went outside and I felt better with the sunlight. My mother became very worried. She took me to a doctor in Netrakona city.

When the doctor prescribed an inhaler, Roni became very upset. He could not believe that he had this kind of deadly illness. Despite having the illness diagnosed as “asthma” by a trained practitioner, he expressed his disagreement with the diagnosis:

I should not use inhaler because mine is only cold-related problem [*thandar somossa*]. I know how this happened to me. I think my problem started with dust. I used to play football a lot. Also I used to ride bicycle. I think the riding bicycle gave me this illness. Fourteen times [colloquial for “many times”] I used to ride the bicycle and fourteen times I used to clean it up after use. Even if there was one bit of dust on my bicycle, I would feel very bad. So I used to clean up that [bicycle] several times a day. During those clean ups, dust has entered into my body. Besides, I used to ride it really fast. That speed forced more dust into the body through my mouth. Whatever the doctor may say, I am a hundred per cent sure that this dust is the main reason for my disease. I had ridden a bicycle for two years and later the problem started. It did not happen before. When I understood, I stopped riding it... My smoking may also have contributed with this dust. This smoking and dust may have created some wounds in my lungs,

wounds that are wet. When I use medicines or get sun, they dry. When I catch cold, these wounds become wet again and stop my breathing.

He later described one of the wheezing attacks, which he attributed to being a “cold.” He told me how he used the sun to “dry” the “wet wounds” and felt better. He described his experience of attending the wedding of one of his Hindu friends. It was already midnight and the wedding had yet to begin⁶. He sat with his friends under a small tin shade in the backyard and had a beer. Although drinking alcohol is socially unacceptable in Bangladesh, people nevertheless drink in concealed places. Drinking usually takes place among friends and during social occasions like weddings. Roni said,

You know, young age people drink a little bit during occasions like weddings. I also had some drinks with my friends. It was a gloomy and rainy day. I was drunk and I fell asleep. Suddenly, sleep vanished and I woke. I saw that the rain drops were falling on my mouth. I could not take a breath. I took off my shirt. At some point a bad cough started and I was fighting to breathe. I could not sleep anymore. I was just sitting there all night. I was walking a little bit here and there. I was eagerly waiting for the dawn. I was waiting for the sunlight to come. I knew that I would feel better with the sun.

Similarly, Uttam, a forty-four year-old businessman and a sufferer of chronic breathlessness, expressed his illness through a discourse of cold and coughing. His first experience of breathlessness occurred while he was swimming in the pond in front of his house. He was enjoying a swimming competition with some friends. Although he had swum across the pond several times before, he could not manage it on that particular day. Everyone was swimming well. But he was too slow and could not keep up with them. At some point he realised that he could not take in *dom* (inhale any air). A few weeks later he had a similar experience of breathlessness during a fight with his older brother. He said,

⁶ Hindu weddings in the community are usually held at night and often took several hours to end.

When I have this problem with breathing [*shashe somossa*], I feel like my heart is coming out of my body. Most of the times, it happens at night. I even went to the bazaar at 4 o'clock in the morning and woke the *daktor* [medicine seller] up from the sleep and asked him to give me medicine.

Here Uttam, in addition to referring to his desperateness, uses another term *shashe somossa* to refer to the illness. Connecting his illness to catching a cold, he stated,

The main root of this illness is sweat. I work all day... in this heat, my body sweats. This sweating makes me weak... The sweat dries up in the body and makes me cold. This is the main root of breathlessness. Another root of this [illness] is dust. You see many children are getting this illness now. The children can easily catch cold. They are often left on the floor when their mothers are busy with household works. And they get cold.

The perceptions of non-sufferers (the lay villagers and local medical practitioners) also reflected a similar explanatory framework to that of the sufferers. On several occasions during my conversations about chronic breathlessness with lay villagers, they brought up the role of dust and cold. In explaining their illness, people would often point to the dusty atmosphere, the cool weather, or the fact that they had performed tasks that required to touch water for an extended period of time such as washing kitchen utensils. The local practitioners also expressed similar perceptions. Ali, a village medical practitioner whom I mentioned previously in my discussion of stigma, told me that many “*hapani* (chronic breathlessness) patients” regularly consulted him. According to Ali, when individuals “get a bad cold”, repeated coughing may put pressure on their breathing organs, leaving scratches on the lung tissue. He believed that their lung tissue was weakened such that the damage was irreparable, and that their breathlessness could not be cured once this damage was done. Explaining why their breathlessness increased during the winter, he said:

Too much cold creates *shashkosto* [suffering of breath]. When it is too cold, the weather has too much humidity or water in the air. ...Someone with those scratches in the lungs can't breathe properly because the tissues in the lungs need to absorb the water first to be able to

hold the air to breathe. Because of those scratches, patients' lungs are unable to hold the air, thus the breathing problem increases [in the cold season].

Ali's explanatory model of cold and chronic breathlessness clearly indicates a similarity to the ones that Uttam and Roni proposed. Previous studies have found similarities in the explanatory models of illness between biomedical physicians and laypersons (see for example, Baer, et al. 2004). In Bangladeshi society, practitioners like Ali hold neither the expertise nor the social status of a biomedical practitioner. However, these people perform the equivalent roles and activities of medical practitioners. Nevertheless, although the explanations offered by these local practitioners represented a specialised elaboration of the illness, they should not be considered as divergent from the lay villagers' understanding of the illness. Indeed, there were evident similarities in the explanations of Jalshiri people and the local practitioners. Irrespective of whether they suffered from breathlessness or not, Jalshiri people referred to a shared set of activities that they understood to be connected with chronic breathlessness.

For individuals with chronic breathlessness, this shared framework represented something else as well. It facilitated a form of re-narrativisation of their illness stories in such a way that sufferers were able to construct a non-stigmatised identity to represent their breathlessness. Their re-narrativisation entailed a crucial relationship between narrative and social stigma. Therefore, before I delve into how the re-narrativisation worked, let us pause and examine some of the key contributors to theory on narrative, social stigma, and illness.

Narrative, stigma, and illness

Garro and Mattingly (2000: 1) describe narrative as "a fundamental human way of giving meaning to experience". Narrativising illness is a kind of storytelling that "portray[s] the interrelationships among physical symptoms and the psycholog[ic]al, social, or cultural context of these symptoms" (Waitzkin and Magana 1997). The study of narrative traditions in

anthropology can be traced back to the collection of life histories and the study of personal experiences (Peacock and Holland 1993). In a way, narrative is central to all anthropological investigation as an anthropologist's primary work is to collect people's stories. Several anthropologists, including a number of clinically-trained scholars, have significantly contributed to this tradition by exploring individuals' illness experiences (Williams 1984; Baer 1987; Kleinman 1988; Mattingly and Garro 1994; Waitzkin and Magana 1997; Mattingly 1998; Hunt 2000; Mattingly and Garro 2000; Gregg 2011).

Cheryl Mattingly (1998) identifies three characteristics of narratives in order to show why they can be useful in anthropological investigations of health and illness. The focus of narratives is on social events that depict individuals' lives, social actions, and interactions with others. Second, narratives contain people's experiences. As Mattingly puts it, "They do not merely describe what someone does in the world but what the world does to that someone." Third, the creation of narrative entails a creation of past experiences. Thus, they are "provocative" in ways that vary depending on the context and on listeners. In this way, an illness story told to a physician may not be exactly the same as it is told to a friend.

The adversities that people face when confronting an illness that does not end, force them to be self-reflexive. When recounting stories of their ailments, they draw upon their past experiences, and constantly engage in a "search for meaning, explanation, and treatment occasioned by illness" (Garro 2000: 70). In the process of recalling their past experiences, they not only remember what previously happened, but reflect current beliefs about their illness. The "remembered self is not independent of the conceptual self" (Neisser 1988: 49). In other words, remembering the past is not merely a reproductive process; it is also a reconstructive one (Bartlett, 1932 in Garro 2000: 70). For these sufferers, reconstructive memories are an important source of understanding their ongoing affliction.

In a similar vein, Cheryl Mattingly (1998) also argues that narratives are not just representations of past experiences. Analysing interactions between occupational therapists and their clients, she finds a homologous relationship between experience and narratives. As Mattingly (1998: 19) puts it, "...narratives are not just about experiences. Experiences are, in a sense, about narratives." The illness narratives that emerged during the interaction between therapists and client were not divergent from the social actions, roles, contingencies, and overall experiences of both parties. She also noticed that various aspects that shaped the therapists' role could not be neatly categorised in terms of the biomedical model that they held. These dimensions of the therapists' role, such as their distinctive attempts to motivate their clients, were "underground practices" that fostered hope in the process of narrative formation.

In studying chronic illness, a number of scholars from medical sociology (Bury 1982; Charmaz 1983; Williams 1984) and medical anthropology (Garro 1992; Becker 1997; Mattingly 1998) have examined the extent to which individuals' lives become unsettled after they are diagnosed with such non-ending conditions. Individuals make attempts to reconstruct their illness narratives in order to develop an understanding of their ailments.

Sociological investigations have examined this construction of narratives in terms of the relationships between individuals' self and society. Medical sociologist Williams (1984), for example, sees narrative reconstruction as "an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society." Williams found that rheumatoid arthritis (RA) sufferers, who were unable to find meaning through clinical understandings of the illness, reconstructed their illness experiences in a particular way that the illness became sensible and meaningful to them. One of his informants, for example, linked his illness to workplace toxicity as the perceived etiologic factor of the illness which could "only" be

interpreted in terms of “his image of society as a place of exploitative relationships and power inequality” (Williams 1984: 198).

Anthropological investigations have explored the subjective perceptions of the individuals and how their subjectivities contribute to the process of the narrative development. In *Disrupted Lives*, anthropologist Gay Becker (1997) describes how individuals attempt to make sense of the crisis in their identities after their normative sense of self has been disrupted by a significant event, such as suffering a stroke or discovering infertility. Her analytical inquiry has special relevance vis-à-vis the experiences of sufferers with chronic illness. Becker argues that when individuals face “disruptive events”, such as being diagnosed with cancer, they give meaning to their experience through developing narratives. They use various metaphors to simplify the process of creating meanings in the construction of narrative. Thus, metaphors help to assist individuals in creating a bridge between the old bodily identity and the new illness identity (Becker 1997). Clearly, narrative plays a critical role in assisting individuals to reorient their illness identity and to make sense of ambiguities surrounding the experience of ailments.

Narrative also plays a key role in shaping people’s experience of social stigma. Erving Goffman (1963: 1), in his seminal work, *Stigma: Notes on the Management of Spoilt Identity*, defines stigma as “something unusual and bad” about someone. Stigma may also refer to “any persistent trait of an individual or group which evokes negative or punitive responses” (Susman 1994: 16). These definitions make clear that stigma carries a connotation of deviance. Certain signs, behavioural patterns and attributes are labelled “deviant” and negatively regarded by society while others are labelled “normal” (Goffman 1963). The social relationship between deviance and normalcy is crucial to comprehending stigma. The former, which is “deeply discrediting,” inversely defines the “usualness” of the latter (Goffman 1963: 3).

Goffman (1963) further observed three types of conditions that attract stigma: physical deformities, character flaws, and belonging to a shunned social group. Leprosy, for example, invariably results in visible changes in the person's physical features, which lack any other logical explanation and thus exposes the affected person to stigma. Goffman's second category classifies individuals' perceived flawed character traits such as dishonesty or weakness. In this sense, stigma is associated with addiction, for example. His third category of stigma refers to the discrimination levelled against a particular racial or communal group. Not everybody, however, agrees with Goffman's categorisations. For example, Veena Das writes,

...The common element among these three types was the notion of a spoilt identity and its management through stances such as concealment, defiance or irony... Although Goffman was sensitive to the differences between the three types of stigma that he identified, the unifying concept of a "spoilt identity" and its management, loaded his analysis towards a highly individualistic rendering of the subject – the individual appears in his analysis as the sole bearer of value (Das 2001: 1).

According to Das, if we are to understand stigma appropriately we need to examine how it is situated in the social networks of stigmatised individuals, rather than (or only) in relation to the individuals themselves (*ibid.*). This is because the 'self' of an individual is not necessarily located in the individual body *per se*, but rather located in the person's cultural and social relations.

Additionally, none of Goffman's three categories correspond well with the experiences of my informants. Even if one considers moments of breathlessness to be a "physical deformity", it is not necessarily a constant condition. The average Bangladeshis do not view breathlessness as the result of any wrongdoing. And since most Bangladeshis, including my informants, belong to one ethnic group, it is impossible to ascertain whether there is any variation in the experience of stigma because of individuals' ethnic identity. I also

did not observe any particular difference in the stigma experienced by people from minority religious groups. However, as we have observed in the stories of Sahara and Julekha, suffering from breathlessness is highly gendered, at least in a rural context. Women with the illness suffer more than their men counterparts, something I discuss further in the following chapter.

The links between social stigma and chronic illness have been studied by many anthropologists, investigating stigmas associated with AIDS (Castro and Farmer 2005), epilepsy (Iphofen 1990), leprosy (Barrett 2005), mental illness (Fabrega 1991), cancer (Hunt 2000; Gregg 2011) and infertility (Inhorn 2004). Anthropologists have examined aspects of identity crisis among stigmatised individuals with chronic conditions. They have also explored the intersections between poverty and stigma.

I turn now to examine the ways a stigmatised individual may attempt to tackle stigma. A critical aspect of stigma is the circulation of information (Goffman 1963). Individuals who are willing to challenge stigma make efforts to stop the information about the illness being broadcast. Gill Green (2009) observes three ways of challenging health-related stigma among individuals with chronic conditions: technological, organisational, and personal. She argues that individuals may use technological advancement as a “camouflage” to mask the illness, thus blocking its public visibility and diminishing the stigma. She describes the use of HAART (highly active antiretroviral therapy) among HIV positive individuals, which also helps to conceal the visible impact of the disease. This form of remedial therapy can bring positive change to the lives of AIDS sufferers. Second, she examines the activities of health-based organisations and their ability to influence state health policy by raising a public voice against stigma. Third, she critically examines the traditional discussion surrounding chronic conditions that stress “loss of self” due to marginalisation and social exclusion. She argues that individuals may reject stereotypes, i.e., the notion of the self that emphasises loss,

through “reflexive narrative reconstructions,” and may create a new and empowered form of self (Green 2009: 33).

Catherine Riessman (1990), in line with Green’s third observation, shows how a divorced man with multiple sclerosis (MS), rather than evincing a loss of self, emphasises some key events of his biography. The man describes himself as “a good husband,” “a responsible worker,” and “a good enough father.” As a way to deal with the stigma associated with MS, this man develops his story in this way to project a positive impression of himself (Riessman 1990). Riessman’s argument shows that individuals may strategically choose the genres of narratives, and select key events of his/her biography, in order to develop a positive self-identity.

This strategic construction of narrative is also present in other scholarly investigations on chronic illness and stigma. For example, in her ethnography on cancer in Mexico, Hunt (2000) explains how cancers and removal of reproductive organs endangered her informants’ social and gender roles. Instead of developing a counter-discourse to resist stigma, her informants strategically developed their illness narratives to re-negotiate their gender and social roles. One woman, for example, who had to have her breasts removed as a result of a surgery due to cancer, blamed her husband’s repeated sexual desire for the development of the illness. This account, consequently, gave her the power to refuse her husband’s demand for further sexual relations, while still retaining the cultural norms such as being a dutiful wife and a good mother.

Another recent study argues that individuals with chronic illness might actually embrace stigmas as a way of dealing with them. In a study on women suffering from cancer in Brazil, Gregg (2011) noted that her informants, instead of rejecting stigmas, strategically embraced stigma in the construction of their illness narratives. For example, they talked about

their own sexual misconduct to refer to why they had fallen sick. This particular strategy helped them to organise narratives in line with the existing cultural and social notions of the illness. However, this was not merely passive acceptance of society's stigmatised labelling. Rather, describing their painful experience with chemotherapies for example, they distanced themselves from the earlier self (before the illness), and also envisaged a new future self, free from both illness and stigma.

The next section elaborates on my informants' re-narrativisation of the illness as a way to counteract the stigmas.

Re-narrativisation

Earlier I mentioned that the local terminologies for chronic breathlessness carried extreme levels of negativity. They shaped the ways in which individuals talked about their breathlessness. An exploration of the cultural meaning of those terms requires more than just mastering the local dialect. In addition to investigating the semantic fields of the terminologies, we also need to understand their social expressions. Looking back at the narratives of my informants, we can see that they have used six terms when discussing breathlessness: *ezma* (asthma), *shashkosto* (a suffering of breath), *hapani* (chronic breathlessness), *taner dosh* (a defect in one's ability to pull in air), *thandar somossa* (a cold problem), and *shashe somossa* (literally, a "problem of breath" i.e., a breathing problem). Even though they have used all of these terms to indicate breathlessness, each carried complex ethnographic meanings and facilitated different expressions.

The term *ezma* is roughly equivalent to the colloquial English term "asthma." One legacy of the British colonisation of the Indian sub-continent from 1757 to 1947 is that several English words (such as chair and table, for example) have been incorporated into the Bengali lexicon and lost their foreign connotations with the passage of time. It is likely that *ezma* is a

derivative of one of these words. During my fieldwork in 2010-11, I noticed several billboards and pamphlets carrying the word “*ezma*” written in Bengali characters and advertising “a successful treatment.” In addition, the country’s only specialised hospital for treating chronic breathlessness is named “*Ezma Centre*” (Asthma Centre), which may also have contributed to the frequent use of the term *ezma* in people’s lives.

Local conceptions of *ezma* differ from the way “asthma” is used in biomedical literature. The term “asthma”, a biomedical category with distinct clinical symptoms, is used to distinguish a specific condition from other types of chronic breathlessness, which I mentioned in the beginning of the chapter. In Bangladesh, the word *ezma*, as used by my informants, was a broad rubric for chronic breathing difficulties. However, to some extent, the term also had “alien” connotations for my rural informants. This was not because the word derived from a foreign (English) language, but because it was associated with an urbanised and educated realm. Thus, the use of the term *ezma* was limited amongst my informants.

The term *shashkosto* (*shash* [breathing] + *kosto* [suffering]) originates in the Bengali language. *Kosto* (suffering) directly reflects the vulnerability of the ailments; thus, the word *shashkosto* labels an individual a vulnerable *sufferer*. However, the ethnographic data shows that fear and stigma evoked by *shashkosto* (suffering from breathing) was considerably less than that implied by the term *hapani*. *Hapani*, a Bengali term that directly described the symptoms and sufferings of chronic breathlessness, is the commonly used term for chronic breathing difficulties in Bangladeshi culture. For this reason, it carries the highest level of fear and stigma of breathlessness and reflects a sense of permanent and irreversible impairment of the breathing organs (lungs). The word *hapani* is so stigmatised that calling a person a *hapani rogi* (a patient of *hapani*) is one of the worst insults that can be levelled at someone, for it exposes the fact that the person has a disabled breathing organ.

Similar perceptions are connected with the term *taner dosh*, but with localised connotations. The term *taner dosh* (a defect in one's ability to pull in air) is probably a term rooted in the local dialect, as I did not hear it in cities. Villagers, mainly non-sufferers, often used this word when they talked about chronic breathlessness, signalling that this term might be associated with symptoms of breathlessness. Non-sufferers described how sufferers were unable to breathe, even though they tried hard to "pull the air". They emitted frightening wheezing *taner* (pulling) sounds due to the *dosh* (defect) affecting their breathing organs. So, when one hears, "this person has *taner dosh*", it indicates that the person has difficulty pulling in air. *Hapani* and *taner dosh* thus reflect a sense of the ailment's permanency in contributing to the impairment of people's breathing organs.

Those who suffered from breathlessness tended to avoid using the terms such as *ezma*, *shashkosto*, *hapani*, and *taner dosh*, as these terms directly suggest chronic breathlessness. Instead, sufferers employed two other terms: *thandar somossa* (a cold problem), and *shashe somossa* (a breathing problem). The first term, i.e., *thandar* (cold), when combined with *somossa* (problem), literally refers to someone having cold-related issues. When a villager in my research site would say, "*amar thanda lagse*" (I have a cold), this was an indication that they had a common cold-related illness. Similarly, sufferers experiencing a mild wheezing while talking to someone, especially a stranger, may describe the illness as *thanda* (a cold), in this way reducing it to a common condition and avoiding stigmatised illness categories like *hapani* or *shashkosto*.

Sufferers whose breathlessness was severe described it as a *shashe somossa* (problem of breath). The first question that one might ask is: how is *shashe somossa* (problem of breath) different from the previously discussed *shashkosto* (suffering of breath)? The main difference is the extent of perceived vulnerability. Suffering of breath/breathing rendered the actual illness experience so explicit that the individual became vulnerable by being at the centre of

the discussion, given that he/she was the person who was suffering (*kosto*). The sufferers, by replacing the word “suffering” (*kosto*) with “problem” (*somossa*), avoided being the focus of discussion pertaining to suffering. The term problem (*somossa*) carried less dangerous connotations than suffering (*kosto*). *Suffering* is laden with enormous emotional content while *problem* – which sounds less specific – allows a more detached relationship to it. Attempts to narrate wheezing as “a cold problem” or “a breathing problem” represented a strategic endeavour to avoid the stigmatised labelling of chronic breathlessness. Medical anthropological studies also show that it is not uncommon among chronic illness sufferers and their close relatives to develop a re-conceptualisation of the illness by using mundane idioms of illness to generate a non-stigmatised identity for the condition. Ria Reis, for example, examined the ways her informants used the concepts of “tension” and “weak spots” to develop an acceptable normalising stereotypical image for their epilepsy, and simultaneously avoiding the negative social stereotyped image of the illness (Reis 2001).

Table 1: Activities behind catching “a cold”		
Sufferer		Non-sufferer
Rain water falling on head	Cold/Cough	Weather (too hot/cold)
Swimming long time		Swimming in the river
Sleeping on cool bed	Chronic breathlessness	Holes in the breathing pipe
Drying sweat on body		Scratches in lung
Working in dusty place		Walking out on a cool night
Strong wind force dust into mouth		Long shower in ponds
Old rooms, cobwebs		Transmitted/hereditary

Furthermore, we may recall the everyday activities with a discourse of cold/cough (Table 1) that my informants stated. In analysing this range of activities, it is possible to examine the notions of “cold” and “cough” as “dominant symbols,” a concept that Turner famously conveyed when explaining the rituals of the Ndembu (Turner 1967). In his view, dominant symbols are autonomous aspects of the Ndembu culture, they inform the central

meanings of rituals, and can be connected to other domains of Ndembu's lives as well.

Similarly, my informants' explanatory models for chronic breathlessness reveal a range of typical, everyday activities connected through cold and cough, which work as "points of junction" in the semantic network of chronic breathlessness in Bangladeshi society (Turner 1967: 32; Good 1977).

The focus of this explanation is on the connection between everyday activities through the dominant symbols. But this explanation fails to shed lights on the relationship between breathlessness and social stigma. By contrast, new light is shed when we examine my informants' narratives from a particular cultural and humoral perspective. Scholars have observed humoral perceptions of illness in South Asian cultures, investigating, for example, how it is not uncommon in South Asia to associate "cold" with breathlessness based on many everyday activities such as bathing (Nichter 1985; Nichter 1987; Mull and Mull 1993; Nichter 2003). Nichter provides one of the best analyses of this concept of illness in South Asia:

Hot/cold is a conceptual framework widely adhered to throughout South Asia. Within Asian medical systems, hot/cold descriptors are used to denote the qualities of people, plants, animals, minerals, places, times, seasons, celestial bodies, foods, medicines, stages of development, gender-based proclivities, and bodily sensations as well as symptoms and types of illness. Symptoms are recognised as signs of internal heat and cold manifest in myriad forms, related to various humoral imbalances. To the lay population, hot/cold reasoning guides behaviours ranging from folk dietetic practice to bathing habits, domestic healthcare to the interpretation of how medicines work, evaluations of the qualities of soil to deliberation about the use of various types of fertilisers (2003: 6).

Nichter recognises that there is no specific pattern in the ways South Asians perceive the notion of "humoral imbalances". Many variations exist from one place to another. Nichter describes how humoral perceptions are embodied in nature. People practice this perception in their day-to-day lives, often without conscious awareness that they are doing so.

However, when people find themselves in a vulnerable situation, they tend to consciously act in accordance with the humoral perception (Ibid.,).

The humoral perception of illness, particularly because of its embodied nature, facilitated the development of the narrative strategy for my informants to avoid stigma. The discourse of cold and cough and the everyday activities listed in the Table 1 indicate the humoral perception of illness, rather than a Western notion of germ theory (see Helman 1978). The informants stated that one may catch cold/cough – and later breathlessness – by taking a long shower, walking in the rain, swimming in ponds and rivers, sleeping in a cool bed, letting sweat dry on the body, walking in dust, or even just by walking on a cool night. These activities are not locally considered exclusive to chronic breathlessness; rather, they are also perceived to be related to the common cough/cold. While non-sufferers express their suspicion that one may catch a severe cold (a common cough) which may later result in permanent damage to the “breathing pipe” causing breathlessness, the sufferers themselves, by contrast, refer to the activities which *caused* them to catch a “cold” (referring to breathlessness as a cough), but deliberately refrain from linking it to *hapani* (chronic breathlessness).

I call this strategy re-narrativisation because of the critical purpose it served to resist stigma by conveying new inflections to received meanings. While talking about their “breathlessness cough,” they cloak their illness in the form of a common cough, which diverts attention away from chronic breathlessness and conceals the actual illness information (Goffman 1963), especially when speaking to an unfamiliar person. Moreover, this strategy draws directly on local socio-cultural notions of cold/cough. As the locals do not consider a common cough to be transmittable or hereditary, re-narrativising allows the sufferers to portray their illness as something not to be feared, changing the identity of the illness from

severe to ordinary, and by extension, motivating the listeners to view the ailment as non-transmittable, non-hereditary, and non-deadly.

Furthermore, another aspect of humoral perception in South Asia, as Nichter noted, is that it is often relational. People may describe one item in relation to others, such as milled rice is considered hot whereas parboiled rice is considered cold (Nichter 2003). This relational characteristic can also be dramatized as a cosmological understanding of bodily disturbance, a cultural perception that some of my informants employed. For instance, we have seen that one of my informants referred to how changes in the moon caused changes in the tide, which were then transmitted into the body because “everything was connected.” Earlier, I traced this notion back to ancient Indians’ cosmological understanding of bodily processes. The perceived relationship between mundane activities and the discourse of cold works to complement the local notion of inter-connectedness, which fits with the cosmological understanding of illness (see also Nichter 1992).

Some of the strategies to resist stigma that scholars have observed in other contexts were less useful for my informants. The three ways (technological, organisational, and personal) of challenging stigma that Green observed could not assist my informants. First, in the case of breathlessness, the use of a remedial inhaler invokes stigma due to its high degree of visibility. Additionally, the distribution of and access to biomedical technology is not even across the society. My informants lived in a place where no trained medical practitioner was available. Second, activities of health-based organisations in Bangladesh are mainly confined to the cities. Even there, my informants’ capability to exercise a political voice is structurally limited due to poor political stratagems. Third, the reflexive re-construction of self is also likely to be less useful because stigma is situated beyond the stigmatised person, resorting in the person’s social and cultural relations (Das 2001).

In order to tackle stigma, my informants did not talk about some specific aspects of their lives to project a positive image (Riessman 1990), or embrace the existing stigmatised identity to develop a sense of hope for future non-stigmatised self (Gregg 2011). Nor did they emphasise some of the positive aspects of their social roles to re-negotiate a non-stigmatised role (Hunt 2000). Instead, they used their awareness of the cultural system of embodied metaphors (e.g., taking a long shower may cause strong coughs/colds) in a strategic way to re-narrativise their illness stories and re-appropriate uses of language that inflected new non-stigmatised meanings into illness identity. This strategy placed them in an empowered position to talk about the illness that constantly disempowers them.

Finally, my informants taught me that it is never enough just to emphasise the importance of appropriately comprehending the native language. Although learning the native language is widely recognised as a critical component in ethnographic research, hiring interpreters is not uncommon. Many ethnographers spend a considerable amount of time learning the language(s) of their study people. But, in addition to knowing the language of informants and understanding its appropriateness, it is equally crucial to establish whether the informants are re-appropriating the language and conveying new inflections in the meaning.

Chapter Four

Making Sense of Illness

Laypersons' views of chronic breathlessness

When I entered his one-bedroom hut made of bamboo strips and mud, Ekram was lying on his bed. An old, wooden, black-coloured handmade bed frame, locally called *chouki*, was the only bed in the house. Next to the bed was a chair with a broken leg, propped up by some broken bricks. Several empty medicine bottles, each bearing the label Butol[®], lay on the chair. A half-made fence made of bamboo strips erected inside the room segregated the space into two sections. Seventy-five year old Ekram lay motionless on the bed, his body outstretched, and his eyes fixed staring at the bamboo roof. Detecting my presence on his doorstep, he turned his head in my direction. He looked at me without saying a word, and turned back to resume staring at the roof. I was surprised by his apparent indifference toward my presence. Until this point in my fieldwork, I had always found the villagers enthusiastic about the prospect of speaking with me, often unusually so. The villagers were especially welcoming toward those visiting their homes, even strangers. Some even compared the arrival of a stranger on their doorstep with “a symbolic entrance of God.” In my experience, even though I was unknown to them, I found that they would take the lead in the conversation. Thus, Ekram’s seemingly unenthusiastic response was unexpected. There was an unusual quietness in his eyes when he looked at me and then muttered to his wife to see what I wanted.

Ekram’s wife, Fuli, came out from the other side of the room divider to greet me. She explained to me that her husband had been suffering from breathing difficulties for more than fifteen years. Sometimes his wheezing became so unbearable that he would try not to “move too much.” On those days, he would spend most of his time in bed. The day I went to meet him was one of these days when he was seriously ill. He appeared to be making an effort to

remain still on the bed, avoiding any sudden movement that would make him breathless. While talking to Fuli, I noticed Ekram was wheezing severely. When I saw the inhaler next to his pillow, I suggested that he take some puffs from the inhaler and try to keep calm. Fuli echoed my request, and asked him to stop talking. I decided to wait until Ekram was feeling better before speaking with him about my research. I went on to have several conversations with both Ekram and Fuli on many occasions. Ekram told me of the many activities that he called “laborious”; these were activities that were a real struggle for him to perform on the days when he experienced severe wheezing. Such activities included many everyday tasks such as going to the toilet, or taking a bath. The day when I arrived on his doorstep was one of the days he called, “especially dangerous”. On these days he was completely bedridden, and unable to do anything at all. Speaking of these “dangerous days”, he referred to himself as “a slave” to his illness and expressed enormous frustration with his life. His illness also greatly affected Fuli’s life. She would often wake in the middle of the night, disturbed by Ekram’s constant coughing and wheezing. The fear of losing her husband plagued her thoughts. She described how she often felt that the nights were too long and the dawns were just too far away.

How do individuals with such unending illnesses explain their condition? In making sense of their suffering, what social strategies do they consider? How do they develop an acceptable explanation of the continuous nature of their illness? This chapter aims to address these questions by examining the explanatory models (Kleinman, et al. 1978; Kleinman 1988) of chronic breathlessness among my informants.

Nature of suffering

Rokeya, a sixty-year-old woman who suffered from chronic breathlessness, was especially sad because of the unexpected nature of the illness. Describing how the illness had become a continuous part of her life she said,

When I carry the water-pot from the river, it starts. It will start without any warning as soon as I start climbing up the muddy road near the river. Even when there is a quarrel between two boys and they are fighting with each other, and I went to see them, I become worried about them. My breathing difficulty would instantly start. If I just give a scream loudly saying “Ya Allah, [he] is beating the child” my breathing difficulty starts. It even starts when I am sweeping my house, or I am near to [cooking] smoke or sitting close to a place in the kitchen where I keep my chilli powder. You have no idea when it will start. When I work with an axe to cut the firewood, at first I feel I have energy and then after a few minutes my breathlessness would start suddenly and I would feel energy-less. Even if it [breathing difficulty] starts to bother me, can I stop? No, I can’t. Without cutting the firewood, how would I cook and run my family [prepare meals, etc.]? When I cannot breathe and I don’t have medicine at home, I keep my body in a bending shape for few minutes: this position comforts me. When it becomes unbearable, I sleep upside down and keep my face into the pillows and just don’t move until I am able to breathe normally again.

This excerpt demonstrates the way the illness, through its continuous and unpredictable nature, can affect sufferers’ everyday activities. For Rokeya, the suffering of chronic breathlessness, following Kleinman (1995: 101), has taken a “routine” form. The ups and downs of this routinisation of suffering are also evident in Ekram’s representation of his illness identity as changeable, such as when he describes certain days as “especially dangerous”. Investigating such fluidities in chronic illness experience, scholars have not only problematized the label ‘chronic’, but have also explored various politics surrounding identity transformations (Reis 2001; Van Dongen and Reis 2001; Manderson and Smith-Morris 2010a). Researchers in this tradition usually express their gratitude to Sue Estroff (1993) for introducing the concept of “chronicity”. Chronicity not only encourages investigating the actual lived experience of chronic illness, but also shows that the dominant temporality

discourse that divides suffering into either *chronic* or *acute* is not apolitical (Manderson and Smith-Morris 2010b). The label of “chronic” brings about an identity change in individuals with a chronic condition, that is, a person who has an illness becomes a person inhabited by the illness (Estroff 1993; Kleinman and Hall-Clifford 2010). Studies focusing on the lived experience of chronic illness show that individuals may not themselves subscribe to such a static illness identity (see the work on epilepsy by Reis 2001)

Another anthropologist, M. Cameron Hay, drawing on her research on individuals suffering from rheumatological and neurological chronic conditions in the United States, illustrates how suffering can vary depending on the visibility of the illness, as well as the extent to which individuals can meet the “cultural expectation of productivity”, that is, whether the person is able or unable to accomplish certain tasks in certain contexts (Hay 2010: 260). Similarly, Ekram’s expectations of performing everyday activities without major obstacles were his own way of assessing the state of his breathlessness.

In order to explain the continuous and simultaneously fluid nature of their illness, my informants detailed their day-to-day experiences of suffering. The aspects they described included their exhaustive occupational lives, lack of familial support, the corruption of local political elites, and social norms associated with gender roles. In expounding these aspects in such a way, they developed an explanatory model of their suffering, which provided them with a socially and morally acceptable understanding of their chronic breathlessness.

Exhaustive occupational life

For most of his life, Ekram had worked as a *bepari*, a job similar to that of a hired farmer. During the harvesting period, villagers hire *beparis* to complete the harvesting work quickly. The role of a *bepari* is critical because of the annual monsoon flood that threatens to engulf the crops before they are harvested. As the crop areas are situated in the lowlands,

floodwaters coming from the highlands quickly inundate the fields, rice crops included. The villagers employ several techniques to protect their crops from the floods. When necessary, they build obstructions (locally known as “dams”) along the river using mud-bags, soil, bamboo sticks, and pebbles. These dams are built in such a way that the water on one side of the dams keeps rising, while temporarily protecting the vast areas of rice fields on the other side.



Picture 6: An under-construction dam

Sometimes, however, the muddy dams are either unable to stem the flow of water, or the water reaches the rice fields from other sections of the river (as happens when there is a bend in the river). As soon as the water pressure bursts the dams, the strong current releases huge amounts of water within a short period of time. Once a large dam bursts the rice fields become inundated soon. This time is a source of intense anxiety for villagers. To refer to the devastating nature of the flood one villager said: “You will have only two to three days after

the dam burst, the total area will be white (referring to currents of the water)...there will be no sign of rice fields...just the water as long as your eyes go.”

In addition to trying to ‘buy time’ for harvesting by building dams, Jalshiri people - especially those who are well-off - also hire people like Ekram (*beparis*) to maximise efficiency of the harvesting work. While working for wealthy landlords, Ekram had performed numerous tasks in his role as a *bepari*. He manually reaped crops with a machete; he then washed the crops in the river water. He was also responsible for threshing the crops with an oxen-driven cart, before drying them in a specially prepared section of the field. Ekram also winnowed the crops to separate the straws and ensure accuracy of weighing the crops. These crops were then put into rucksacks before Ekram finally carried them to the landlords’ inventory.

During the interview, he particularly stressed the burden of his responsibility to weigh the crops. The villagers placed a great deal of importance on the job of weighing crops, because the crop yield often represented a farmer’s yearly income. Also, crops sometimes took the place of hard currency, and farmers usually received their remuneration in particular amounts of crops instead of paper currency. Many villagers often buy goods from hawkers paying with rice. For these reasons, villagers always sought an accurate assessment of the crops they had harvested. In Jalshiri, *beparis* were considered highly skilled, and it was they who were trusted with the important job of weighing the crops.

During the harvesting period, Ekram had often performed the job of weighing the crops using a manual scale made from a strong wooden rod. The weighing machine was approximately 30 cm long and at its two ends were two pots, usually made of aluminium or bamboo strips and attached by ropes. One pot would be filled with stone measuring a particular weight (in kilograms). The other pot at the end of the wooden rod would be filled

with whichever crop Ekram was weighing. Attached to the centre of the stick was a small rope which Ekram would use to pull the wooden stick upwards. While pulling the scale upwards, his task was to carefully ensure a horizontal balance of the rod, as any imbalance between the stone weight and the crops in the pots would cause the stick to swing. It was critical that he ensure proper scaling by maintaining a horizontal balance of the rod as much as possible; something he had to

do just by looking at the stick.

The mechanism of the scale looked similar to the Scales of Justice albeit the former had no stand attached; instead of a stand, the scale had to be pulled up manually. Ekram told me how he had sat on the pile of dusty crops for several hours while performing this arduous work. Moreover, it took much of his physical strength to hold the scale steady while ensuring that the wooden scale-stick was correctly balanced.



Picture 7: A farmer with his dusty crop yield

According to Ekram, the dust from the crops had “pierced” his lungs. He felt this was the result of his work which led him to ingest enormous amounts of dust. He suspected that the delicate nature of his lungs rendered them irreparable following such damage. He also mentioned how he had spent a long time in sludge and cool places as part of his work cutting

and washing crops. According to Ekram, all these factors contributed to the development of a strong “cold”, which later “transformed” into chronic breathlessness. Fuli also shared Ekram’s belief that his work as a *bepari* contributed to his health problems. She made a point of telling me, “during the time [of harvest], many *bepari* used to come to our house. I have seen all of them struggle to breathe”. She added that when these visiting *bepari* spoke, they would emit ‘scary’ wheezing sounds.

Another informant Borendra described a similar story. Borendra was the father of my research assistant, Salil, and at 80 years of age, he had suffered from chronic breathlessness for more than twenty years. At the time of our interview, he had stopped working and spent most of his time at home. As such, the family was dependent upon Salil’s income. In talking about his illness, he expressed his frustration that he was unable to perform many of his everyday tasks. For instance, after taking a bath, he would become tired very quickly; when he squeezed his cloths to remove any extra water, he would become breathless. His breathlessness also meant that he was unable to stand being anywhere near the kitchen during cooking time. He had given up smoking ten years ago, following the advice of a village doctor, who told him that giving up smoking would cure his stomach gas. These days, if someone smoked a cigarette in front of him⁷, he would start wheezing. Instead of smoking, he would consume paan (beetle quid, a form of smokeless tobacco) after a meal, which he felt enhanced the flavour of his food.

Something that Borendra found particularly upsetting was the fact that sometimes he was unable to carry the water-pot (*bodna*⁸) to the toilet. Because of this, he was forced to ask

⁷ In an earlier study, I have explored the ways tobacco consumption in rural Bangladesh is highly influenced by the cultural forms of gifting, sociability, and collegiality (Roy 2012). Thus, it is not always possible for my informants to avoid passive smoking.

⁸ *Bodna* is a local water carrying pot used in toilet. After defecation, use of water instead of toilet paper is a common practice in many South Asian countries.

his daughter-in-law for help. While speaking of this, he sighed and with palpable sadness said to me, “[Now] I cannot carry two kilo.” This remark not only represented his present frustration with his inability to engage in so many day-to-day activities, it also referred to the fact that as a hardworking labourer for most of his life, he had now become dependent on others. He told me,

In my life, I have performed *abnormal* work (too much labour) [stress is original]. I never gave my body a rest. I even worked without having meal properly. From such [heavy] work, this (chronic breathlessness) started.

Like many others, Borendra and his wife had fled East Pakistan during the 1971 war of liberation from West Pakistan. They took shelter in a refugee camp in a neighbouring province of India, and it was here that Salil was born. After the birth of his son, Borendra decided that he could not remain in the refugee camp with a newborn baby. He managed to escape the refugee camp and get a daily labourer job in the local community. He repeatedly stressed his extensive work in rice lands, where he was poorly paid, despite the labour intensive nature of the work. He was therefore forced to take a second job in a garment tailoring shop nearby, and he continued working both jobs until the end of the war. He returned to his home in the new Bangladesh only to find that his house had been demolished and looted by some of his Muslim neighbours who supported the Pakistani military during the war. The looters also had captured most of his land and he had no choice but to let them keep it. They gave him some money for the land, but the amount was considerably less than the market price. As he had to start again from scratch, he decided to return to India, leaving his wife and son behind in Bangladesh.



Picture 8: Working in a sludgy field

Borendra attributed his breathlessness to his continued work in farmlands and the tailoring shop. Back in India, he first resumed his work at the tailoring shop, and then later took on work as a farming labourer. He remained working in India for fifteen years, during which time he sent money home regularly and visited his wife and child once a year. According to him, dusts and crop residue regularly entered through his nostrils and mouth during the farming activities, and often caused him to suffer from a cough. For many years he continued working in both jobs despite the fact that he had an ongoing cold. After finishing a long day's work in sludgy rice fields, he would then rush to the tailoring shop in the evening. He stated, "I did this abnormal (too much) labour for many years. Suppose I planted crops all day and [soon after finishing] I ran to the tailoring shop in the evening without having any time to eat or take some rest. How can you eat when you know that customers are waiting at the shop?" The tailoring shop became very busy during the religious festivals, such as Durga

worship, when several people wanted to have their clothing made at the same time. On these occasions, he would work over twenty hours a day, often leaving the tailoring shop at midnight. The sewing machine he used for his work was always cold and even colder during the winter season. He felt that this exacerbated his cough, which then went on to become a permanent breathing problem.

Lack of support

Most informants were not as fortunate as Borendra in terms of receiving financial and social supports from their family members. Borendra's son Salil took care of him. On the other hand, Ekram and his wife Fuli longed for a child. During our discussions of their childlessness, they became extremely distressed, and their expressions remain etched in my mind. The question of whether anyone else was living with them brought a palpable silence to the room. Ekram tried to hide his sadness by looking at the other side of the bed while Fuli wiped her eyes with her sari. It was clear that my question had inadvertently brought a source of lifelong grief to the surface, reminding them of their hopes for a child, and the impact that childlessness continued to have on their lives to this day.

For Fuli, her husband's illness, together with the absence of a child, meant that she sometimes had to forgo basic necessities. When Ekram was bedridden because of his wheezing, for instance, Fuli spoke of how there was no one to go to the bazaar to buy groceries. Fuli also shared a story of a painful leg-injury that had left her debilitated. About a year ago, while walking on a muddy path in the village, Fuli slipped and broke her left ankle. The extreme pain rendered her bedridden for the next few days. The painkillers she bought from a rural practitioner in the bazaar proved useless. Soon she became unable to take weight on her left leg at all. Ekram decided to borrow some money from his neighbour so that he could take Fuli to the city to see a trained physician. But Fuli refused to go. She provided

several excuses to justify her decision, saying that it was always very expensive to travel to the city, and that the city traffic frightened her. Pointing at Ekram, Fuli said: “You have no idea how much it would have cost!” After a few days, she found that she could not walk at all, and so visited a bone-setter in the village. The bone-setter condemned her for leaving the consultation so late. She tied some small bamboo sticks to the broken ankle and asked Fuli to leave them there for a month. After the month was up, Fuli found that she had gained a little strength in her leg. But she soon discovered that her leg appeared “curvy”, not the way a leg should look at all. Through tears, she explained for me:

My sister’s son occasionally came and helped me to walk for few days. After a few days, I tried myself and staggered for weeks. Later I could not walk [by myself] anymore; I started using this [showing the stick]... We have no one to call when we are in danger.

In addition to affecting Fuli’s life, childlessness also greatly affected Ekram’s suffering in his occupational life. After Fuli noticed that many other *beparis* suffered from a problem similar to Ekram’s breathing difficulties, she told Ekram that he should leave his farming job and find other work. She blamed Ekram for not listening to her, and also for his subsequent breathlessness. Ekram remained quiet while Fuli heaped blame on him. When he finally spoke, he sounded frustrated, saying that he could not have just left his job without having a means to support the family. It seemed that Ekram had always been burdened by anxiety about the future. He constantly worried how he and Fuli would survive in old age, particularly given that they had no children. Because of this, Ekram wanted to work to save enough money so as to avoid financial problems in the elderly period of their lives.

While Ekram’s lack of support was felt through his childlessness, for Rokeya, whom I mentioned earlier in the chapter, the lack of support took on a different dimension. Since the death of her husband thirty years ago, Rokeya lived a life of struggle. Her husband was a runner (postman), and his job required that he travel by foot to distribute letters and parcels in

the area. Following her husband's death, she was approved an allowance of 1500 taka (\$21) per month from his pension fund. Every month she had to go to the post office in Netrakona district town to get the money, and this process was always costly. The people at the post office would always ask for "tips", and after the bribe together with the transport costs, she would often be left with 900 taka (\$13). With three sons to care for, it was impossible for her to live on this scant amount of money, even with the low cost of living in rural areas taken into consideration. Recalling those days she said, "I even ran out of kerosene to light the lamp and I had to send my son with the [empty] lamp to the neighbours [to get some kerosene]. Many of them were kind and they helped us." For several days she would be in distress. She lamented the absence of her husband day and night, and often fainted while crying for him. She remembered the situation as "falling in a sea full of cries with no help."

Rokeya knew that she had no one but her three children. She knew that raising them properly, and ensuring they did not starve, was the most important job of her life. She sought assistance from her husband's other brothers, but no one gave her any help. She told me, "I cried more when I raised my kids, than what I had cried after he (her husband) died." When Rokeya recalled how she had collected food for her sons, she burst into tears. She had to go to the jungle to cut firewood with an axe, an activity that was mainly performed by men. She would go to the barren marsh fields near the village and collected *koi*, a type of moss, to cook as a curry for her family. Sometimes she went fishing in nearby ponds using a small bucket to catch some tiddlers so that her children could have some fish with their meals. She even kept a cow as livestock, even though not many women could do that job at the time. She milked the cow herself and sold the milk to other people in the village, again performing a job that was not usually done by a woman. After her boys finished primary school they sought work opportunities as assistants to the farming labourers. But when they were unable to do the work properly, they were sent home. These circumstances and her acute sense of vulnerability

forced Rokeya to take up work as a maid. Throughout all this, Rokeya often felt unwell, but she always tried to put the care of her children ahead of her own wellbeing. She knew that without them, there would be no one to take care of her when she reached old age.

According to Rokeya, the extensive work she was forced to perform meant that her body was weakened because she could not take care of herself. Unable to give her body adequate rest, or proper nutritional foods, she became weak and easily vulnerable to illness. In our interview, Rokeya particularly stressed those activities that required her to deal with water and cold. She referred to work such as fishing and collecting moss in the cold winter dawns, activities which she believed were responsible for the strong cold/cough that developed in her weak body; an illness which later became breathlessness.

Corrupt practices of local elites

During our discussions, my informants often brought up the illegitimate activities of local political elites. Many of them viewed this aspect of village life as intricately connected with much of their suffering. Ekram, for instance, faced great economic hardship after he left his job of working as a farming labourer. He had heard there was a local government relief program, which provided financial assistance to poor and distressed elderly people. He also discovered that some local political elites unofficially administered the project. One of these people lived not far from Ekram's own house, and so he went to speak to this neighbour. When they met, Ekram requested a card, a form of special identification that one needed in order to receive assistance. He asked several times, but each time he received an answer that he was not "poor enough" to be eligible for the card. Later, Ekram discovered that some recipients of cards had actually bribed the elites. He tried once again to obtain a card from his neighbour, but this time he was told that all of the cards had been distributed and there were none left. Ekram was acutely disappointed, as he had sincerely hoped to receive financial

assistance to ease his everyday suffering. He had also planned to spend some of the money on medications. He condemned the local political elites for “causing all of the miseries” for the poor in the area. Initially, I thought that such an over-arching accusation was simply a metaphorical expression of his frustration about his unsatisfactory dealings with the elites. However, it soon became clear that there was more than just metaphor at play, because of the extensive power the elites held in the village.

Several villagers referred to the improper relationship that existed between local elites and people who worked in the local government office. This relationship allowed elites to keep a firm grip on many of the government’s activities in the village, such as accessing the government’s funds for building the dams. Given the overwhelming nature of the flood and the importance of the crops as income for this mono-cropping community, the government regularly allocated dam-building funds to farmers. While funding was ostensibly for local government spending, in practice, it was the local elites who were responsible for funds related to the building of dams. The elites employed people and arranged other necessary logistics such as hiring boats to bring pebbles and mud bags. Ekram accused the elites of deliberately making the dams weaker and causing them to burst early, resulting in the tremendous suffering of local people. He condemned the misuse of local government funds that resulted in insufficient mud and pebbles, which were essential for strengthening the dams. According to Ekram, the elites spent only 200,000 taka (\$2800) on the construction of the dams, whereas the total allocated fund was 1,000,000 taka (\$14,300). The rest, he said, was “pocketed” with the help of local government personnel.

Without enough mud and pebbles, the dams were inevitably fragile. These fragile dams often burst before completion of the harvest, with serious ramifications for the livelihoods of local farmers. In such instances, many farmers flee the area and seek other sources of income in different areas. In fact, several years ago, when Ekram decided to leave

his regular job of *bepari*, the decision came as a result of an early dam burst, rather than due to his wheezing. That dam right next to the bazaar was one of the most important dams as it protected the vast areas where many villagers including Ekram's landlord had their rice fields. The dam broke very early, and crops were inundated within a couple of days. The local people were particularly angry at the elites who were responsible for building the dam. Like Ekram, many farmers received only meagre remuneration from their landlords. Farmers who had cultivated a small amount of land for themselves also lost their crops. These farmers, also like Ekram, were left with huge debts that had accumulated due to purchases from several shops in the bazaar throughout the year. The village medical practitioner who gave Ekram medication on credit, for example, began asking for money following the burst of the dam.

Ekram realised that if he just stayed at home, he would never be able to repay any of his debts. There was no farming work in the village which he could do. In addition, he was embarrassed to work as a daily labourer in the village bazaar as everyone in the village would recognise him performing such low status work. Left with no other option, he joined a small group of fellow farmers and travelled to a distant place in an eastern district to commence work on a construction site, located near a river. As part of this work, Ekram and his colleagues extracted sand and pebbles from the waterways and streams, and put them in old plastic bags before carrying them to a warehouse close to the shore. These bags were then transported to Sylhet City where they went on to be used in the construction of high-rise buildings. Ekram was initially hesitant to talk about this job. I understood his hesitation to mean that the low social status associated with being a daily labourer caused him some discomfort. Once a proud farmer, held in high esteem by his fellow villagers for the critical role he played during the harvesting period, Ekram had become a daily labourer whose hard work went unacknowledged. His construction job was also poorly paid, and he was constantly worried about whether he would be able to send money regularly to his wife at home.

According to Ekram, his barefoot work in the water and dirt exacerbated his breathlessness greatly. Sometimes he coughed constantly, and his shortness of breath resulted in many sleepless nights. Because of his breathlessness, his employer eventually sent him home.

As such, Ekram finds his suffering to be closely connected to the local elites' illegitimate activities. Although it was not possible to stop the flooding permanently because of its monsoon nature, it was certainly possible to delay the water by making the dams stronger. This would also buy some valuable time for the poor villagers to harvest their much-needed crops. The elites also denied Ekram financial assistance because they did not receive bribe. Their activities made Ekram so frustrated that he commented: "Humans are worst terrorists of all... I just have Allah now. Whatever long I live, I have to rely on Allah." Even though the corrupt activities of the elites took place locally, their power rooted outside the local area. The elites were also members of the national political party that governed the country, enabling them to exercise enormous power in the village. Due to their influence over the local government as well as the local law enforcement authorities, they often threatened the villagers. As such, the villagers could not complaint about the elites' illegal activities even though they were very angry about the corruption.

To fulfil gender norms

Among my female informants, the role of gender norms, and the effect of such norms on their experience of suffering was a common theme. Gender norms played out not only in terms of their experience of physical ailments, but also across the overall trajectories of their lives. Recall, for instance, Fuli's experience of living with a broken ankle. Even though poverty was constantly present in the day-to-day lives of the family, Ekram did borrow money from others so that he could go to Mymensingh town three times to consult a trained

physician for his breathlessness. Fuli, by contrast, had only consulted a bone-setter in the village. She herself refused to go to the city because it would cost Ekram so much money.

During my fieldwork, I heard numerous other stories of how men were prioritised over women in families. One of these stories was articulated by Rahela, a 50 year-old woman, who spoke of how she stopped cooking regularly because “there was no one at home [to eat].” Her husband, a farming labourer, always left home very early morning and did not come home until late at night, often after having dinner at the landlord’s house. On many occasions, he did not come. He slept in the landlords’ house. Sometimes he worked in other distant villages and did not return for a week. On those days, Rahela did not cook regularly, and this was not only because there was nothing to cook at home. Sometimes she did have potato or other vegetables. But she did not see any point in cooking, because there was no one at home but her. Often she cooked only rice and kept the rice moist by pouring water into it. This technique allowed the rice to keep for a few days, so that she could subsist on rice with salt and water for that time. The moist rice was always cold, and it was even colder in the winter. According to Rahela, eating that watered-rice (*panivat*) caused her to catch a strong cold, which eventually resulted in her breathlessness.

Forty-eight year-old Joya was a mother of two children, one son and one daughter. She was married to a jewellery worker thirty-five years ago. Before marriage, she only occasionally performed household work, such as making tea for guests. Her mother loved her so much that she never let her do anything. After Joya came to her husband’s family after marriage, she found that her body was unable to tolerate the extensive amount of work that she was expected to perform. Under the strain of the arduous housework, she became ill. During our interview, she mentioned a number of times that she was not ill before her marriage. Yet soon after she arrived in her husband’s home, her mother-in-law ordered her to do all household works such as cooking, and cleaning. Her day began at 4am, while everyone

else in the family would still be asleep. First, she would have to take all the previous night's dirty utensils to the pond to wash them. At that time she would also have to bathe in the ponds, a task she could never escape, even in winter. Her mother-in-law had given her very strict instructions that she had to "wake up" the gods in the morning after taking the bath.⁹ The mother-in-law herself never woke up in the morning because she was too old. After waking up the gods, she would walk to the end of the village to fetch drinking water from tube-well. Once she returned to the house, she would immediately begin preparing breakfast for her husband, so that he could eat before he left for work. Soon after breakfast was ready, she had to prepare hot water for her mother-in-law to freshen up. Later she became busy with preparing lunch which involved tasks such as washing vegetables in the ponds. During the day, she also sometimes took all the dirty clothes to the pond to wash them with a bar of soap. In this way, Joya's entire day would go by, with no time to take rest. Nor could she avoid going to bed late. All this work often made her tired and restless, but she did not dare to complain, as she feared to the wrath of her mother-in-law. Her mother-in-law often shouted at her for being "slow" at her work. Even when her mother-in-law had died ten years ago, Joya never hired a maid as her husband could not afford it. Her daughter did ease the household burden for a while, and used to help with much of the work, but she got married a few years ago.

According to Joya, her illness was the result of all the housework that she had been forced to perform for so many years. There was too much work and she was not able to take rest. She emphasised the work of washing clothes in the pond and fetching drinking water from tube-well, which, she stated, caused a bad cold. Also, under the strain of the heavy workload, she often became faint and her children would pour water over her head to help her

⁹ Her house had a small alter where pictures of several Hindu gods and goddesses were kept. Each night she would put them asleep by covering the pictures with a piece of cloth. In the morning, she would uncover the pictures to wake them up.

recover. This continuous pouring of water on her head, she said, exacerbated the cold and created her chronic breathlessness. She asked her husband to take her to a doctor a number of times, but her husband did not care. He was always busy, and she did not want to nag him with repeated demands. She thought to herself that if the cold healed on its own, it would be better anyway. Plus, this way her husband would not have to spend his hard-earned money. She said to me, “He works so hard all day... My mind does not want to bother him too much by just telling about my illness.” Initially, Joya experienced wheezing only at night. But soon the breathlessness affected her during the day too. After some time, her husband took her to a village doctor, though according to Joya, it was already “too late.” The illness became very strong in her body because she could not take rest when it was needed, and she could not see a doctor when it was needed. She said, “I feel very sad when I cannot take a rest... when breathing difficulty starts, I cannot take that rest [weeping]...”

All of these three women’s personal sacrifice and patience fulfil widely-held social ideals of “the two virtues of Bengali womanhood” (Jahan 1975: 10). Bengali women hold a submissive status in most of their social roles. They are even more vulnerable in their role as a daughter-in-law, especially those who are newlyweds. A woman’s status as a newlywed daughter-in-law is considered inferior to all other women in her husband’s family, with whom she lives (Jahan 1975). Many consequences of this inferior status were present in Joya’s story. According to Joya, the lack of rest made her body weak in a way that attracted ailments like strong cold/cough, which later turned into chronic breathlessness.

Making sense of the illness

The issue of how people make sense of their illness is a major theme in anthropological investigations. Evans-Pritchard’s classic work *Witchcraft, Oracles and Magic among the Azande* is an early example of such interest within the discipline. He explained

how the Azande employed a notion of witchcraft to explain their illness and misfortune. Perceptions of witchcraft among the Azande were not based on a concrete, straightforward concept that implied a supernatural power; rather such understandings of witchcraft were complex and simultaneously flexible in terms of their applications within the community. The concept of witchcraft was ever-present in their culture, as well as in their environment, and had the potential to harm or cause misfortune to any person at any time. Although the concept of witchcraft had a pervasive presence in the community, members of the community were still able to distinguish between natural occurrences and the phenomena that were consequences of magic or witchcraft. For the Azande, the notion of witchcraft provided both morally and socially acceptable explanatory models for illness and misfortune (Evans-Pritchard 2010).

In order to explain their chronic breathlessness, my informants referred to several dimensions of their lives. I have detailed their stories of exhaustive occupational lives, their struggles to live without familial support, the devastating consequences of political corruption, and gender inequality. A common theme that cuts across each of these dimensions is the experience of overworking and the repercussions of this in terms of their illness. According to my informants, the extent and nature of their labour was both undesirable and unhealthy, and it was this that eventually caused their chronic breathlessness. This appeared to them to be a convincing explanation for their illness, partly because of the way such discourse simultaneously addressed the cultural, and the politico-economic realities of their lives.

Several cultural practices emerge in this explanatory framework of overwork. First, the explanation concurred with the existing humoral perceptions of illness in the community. In the previous chapter, I detailed the ways local people, employing a humoral perspective, associate many everyday activities that are associated with cold, wetness, and dust with their breathlessness. The villagers suggested that activities such as walking in the rain, spending

time in cool weather, or working in dusty places may cause a cold/cough. The stories of all informants in this chapter corroborate the association between such activities and the development of a cold/cough. In his story, Ekram placed particular emphasis on his years of work in dusty pile of crops, sludgy rice fields, and barefoot work in the riverside construction site. Borendra, in addition to referring to his farming work in dusty and sludgy places, stressed the long hours he worked using a cool sewing machine, making a point of telling me that this machine became even colder in the winter. Rokeya pointed to her many years of hard work trying to feed her children, referring especially to the work of fishing and the collections of mosses from barren marsh fields in the cold winter mornings. Joya suggested that chores such as washing dishes in a cold pond at dawn, fetching water from a tube-well in the morning, and the pouring of water on her head during a fainting instance all contributed to her developing a cold and subsequent breathlessness. Due to the underlying humoral notion that associated these tasks with water and dust, they were then interpreted by my informants as factors that caused them “a bad cold,” which gradually “became” chronic breathlessness.

Previous studies have showed that it is not uncommon for illness narratives to pivot around environmental factors to conceptualise the development of chronic illness (Garro 1995; Whittaker 1998; Wind, et al. 2004). In her study of a Canadian aboriginal community, Garro (1995) found that in order to explain their diabetes, her informants referred to broader social, and environmental changes in the community that they attributed to contact with white Europeans. Similarly, Whittaker (1998) describes how members of a suburban community in Australia explained the development of cancer by connecting it to pollution from a land-fill dump site and radioactivity resulting from previous mining activities. In researching laypersons’ perceptions of asthma in Alaska, Wind and colleagues (Wind, et al. 2004) found that their informants viewed many aspects of an indoor lifestyle (such as smoke, dust, and cooking smoke) as well as the outdoor environment (such as cold weather, dust, and water

pollution) as causal factors for asthma. Likewise, my informants also referred to the environmental aspects of dust, and cold to conceptualise their chronic breathlessness.

My research also points to the way cultural norms influence the experience of suffering. Both Ekram and Borendra stated that they continued working too hard – even though they deemed this undesirable and unhealthy – because they needed to support their families. In other words, they viewed their work as a moral responsibility, necessary for the wellbeing of the family. Other family members also recognised the importance of this contribution. When Borendra was forced to return to Bangladesh following a substantial decline in his health, his son Salil began supporting the family and taking care of his father (Borendra). Even though Salil himself did not earn very much working in a grocery shop in the bazaar, he took his father to the city three times to consult with trained physicians.

Anthropologists have observed of how chronic illness can legitimise people's transitions in roles and responsibilities (see, for example, Heurtin-Roberts 1993; Hunt 2000). Heurtin-Roberts' study among African-American women shows how individuals with hypertension may use their illness as a tool to manage the behavioural environment (quarrels, for instance) in the family. Her study also describes the ways hypertension was used to mark individuals' life stages, and roles they performed (Heurtin-Roberts 1993). Similarly, in her study on cancer in Mexico, Hunt (2000) described how one informant, who was the only family breadwinner, had to stop working after he was diagnosed with cancer. Recognising his past contributions, family members granted him an exemption from the earlier obligations and renegotiated his roles in the family. Likewise, even though Borendra had to return from India due to his illness and became dependent upon Salil, his position in the family was positively renegotiated. Salil stated that it was his (moral) responsibility to take care of his father because his father had earlier done the same, showing the legitimisation of Borendra's changed roles.

The stories also illustrated another cultural aspect of Bangladeshi society: the burden of childlessness. Ekram's experience of suffering, for example, has a strong cultural significance due to the particular way Bengali culture regards the importance of children (essentially a son) as a form of social support. Because society considers having a child, especially a son, as a support in life, Ekram viewed his own lack of a child as inextricably linked to his overwork. Ethnographic studies in Bangladesh have explored the deep frustrations, helplessness, and sufferings caused by unwanted childlessness among poor people (Nahar 2007; Nahar and Richters 2011; Van der Geest and Nahar 2013). For Ekram and his wife their distress was not simply because they did not have a child, but because they did not have a son. In general, Bangladeshis generally do not support the concept of aged-care centres, viewing it as the responsibility of sons, especially the eldest son, to take care of elderly parents. Jalshiri villagers often commented that aged-care centres were for those who had been abandoned by their children, a sign that the children had refused to perform their (moral) responsibility to care for their parents. The support that a son provided to the family went beyond simply caring for his elderly parents. During my stay in the village, I observed several verbal tussles between villagers. One of these tussles I encountered was between two men in their forties. Each was swearing at the other, but one man was displaying unusually bold expressions. In an explicit voice, he threatened the other saying: "I have three sticks (sons), come (to fight) if you want...whenever you want." This man's reference to his sons was a show of his strength in the event that there was to be any physical abuse. In this way, a son was seen as a form of crucial support; a son was someone who could help with life's struggles, be it a fight with a neighbour, helping to run the family, or just dealing with everyday difficulties. Several studies have documented these and other complex factors associated with the preference for a son in South Asian cultures (see, for example, Lamb 2000; Jeffery and Jeffery 2002).

Cultural norms associated with gender roles have also influenced my female informants to engage with overwork. Joya's story, for example, refers to the role she had to fulfil as a daughter-in-law, and how this role negatively impacted her health. Many scholarly investigations have explored the submissive status that Bengali women hold in different stages of their lives (Jahan 1975; Roy 1975; Rozario 1992; Lamb 2000). Women may also exercise power over others in some familial relationships, as does a mother-in-law with her son's wife, for example (Roy 1975: 101-103). In Joya's case, due to the hierarchical relationship between herself and her mother-in-law, she did not see any alternative but to obey her mother-in-law's instructions to do all the household chores. Because of her vulnerable position in the family, and the existence of gendered norms that dictated that she – as a married woman – perform these duties; she was compelled to work beyond her limits, unable to rest even if she became tired or unwell.

In addition to these cultural factors, the theme of overwork also demonstrated the marginalised politico-economic reality of my informants' lives. When I asked Borendra why he continued working two jobs, he replied, "To run the family, [suppose] you need 100 taka, I [used to] earn 10 taka. Where does the rest 90 come from? There is no way but work more." In this way, the lived experience of economic scarcity influenced the overall trajectories of their lives. Most of the villagers I spoke with had always bought necessary goods from the village bazaar on credit. In fact, the shop-keepers and the villagers came to an arrangement in which the debts would be paid after the harvesting period, a time when the villagers usually had some money in hands. As described in Ekram's story, many farmers, Ekram included, fled the village knowing that they would not be able to repay their debts when their crops were lost in the flood. Similarly, as a widow, Rokeya only received 900 taka (\$13) per month from the post office to run her family of four. This was an impossible thing to do and so she had to look for other work, even if that meant engaging in activities that were considered to be

the domain of men in the village. Even after working so hard, she remained poor. Connecting her economic scarcity with breathlessness she said, “When I think a lot where I would eat, how would I get food or how would my days will pass (without money), then my wheezing starts” Dire economic circumstances left her with no choice but to work extensively, hoping to earn more and to improve the family’s circumstances. As Rokeya’s account suggests, hard work triggers breathlessness, but so does the anxiety about poverty. In turn, this anxiety leads to more hard work. From such stories, we glean a sense of the vicious cycle in which poverty, poor health, and low social-status continually reinforce one another.

My informants also suffered from the consequences of corruption among the local political elite. Ekram’s story shows how the dam that burst early on account of insufficient building materials brings the widespread repercussions of corruption. As a result of a dam burst, Ekram became a daily labourer and worked in construction, which was a step down from his farming activities.

The corruption of the local political elite can also be analysed from another perspective. During my stay in the village, I noticed people often using the term “corruption” in an idiomatic sense when talking about many of their everyday disappointments. For example, if the people thought that they had paid more for a service than it was worth, they tended to express their indignation through a discourse of corruption. Once when I was walking in the village bazaar, I stopped after I saw some posters advertising an urban clinic. I was pleased to note that the clinic was offering a special discount for people from this particular area. Whilst I was looking at the poster, a young male passer-by commented, “All these are butchers; they would cut your neck by asking huge amount of fees and then [they] will give a tiny discount.” According to him, this discount campaign was only “a trap”; the clinic was only after money, and the practitioners had no interest in providing better treatment for people. He further commented that the government should have taken “those greedy

doctors (referring to the posters of the clinic) down.” But the government would never take action against them as they (the government officials) are all “corrupt” and accept bribes from the clinics. There were villagers who travelled to cities for various purposes and had had spent more money than they intended to get the job done. They would express their dissatisfaction by referring to the “corruptive” practices of the officials that they dealt with. This way of expressing dissatisfactions through the portrayal of “corruption,” reflected how they imagined the state in “the minute texture of everyday life” (Gupta 2006: 211).

Additionally, anthropological studies in Bangladesh have also showed that poor people’s articulation of physical symptoms may actually refer to the broader social context of their lives. My informants did this through repeatedly referring to their “weakness” and “worries” in descriptions of their suffering. Joya, for example, mentioned how the extensive household chores made her weak. Similarly, Ekram and Borendra also spoke of weakness, and talked about their constant worries of how they would support their families. I contend that these expressions of “weakness” and “worries” are idiomatic and carry deeper underlying meanings. These idioms were “metaphors of economic, social, and political deprivation” (Rashid 2008: 111). These forms of deprivation influenced the trajectories of their lives extensively, even more than the continuous suffering of their chronic breathlessness. As such, the theme of overwork also represented the informants’ structural vulnerability (Quesada, et al. 2011), and their frustrating experience of living with marginalised politico-economic conditions (Singer 1986; Bourgois 1995; Farmer 1996).

There is an extensive discussion in medical anthropology of how individuals express their everyday social, political, and economic distress through narrating their experience of (chronic) illness (Becker 1997; Hunt 1998; Hunt 2000; Mattingly and Garro 2000; Schoenberg, et al. 2005; Mendenhall, et al. 2010). As such, my informants’ explanatory models of chronic breathlessness reflected ordinary experiences of their lives, allowing them

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to go beyond of their somatic ailments so they were able to incorporate their social suffering and to express their chronic dissatisfactions and frustrations (Kleinman, et al. 1996). Thus, following Nichter (Nichter 1981; Nichter 2010), chronic breathlessness was an idiom of distress for my informants. It is possible that for my informants, chronic breathlessness, because of its embeddedness within everyday life, appeared to them as the most appropriate mode to express an array of distressing factors that routinely contributed to their experience of suffering (Nichter 1981; Mendenhall, et al. 2010).

Furthermore, there were many similarities in my informants' observations and the discussions of chronic breathlessness in medical and public health literature. According to the WHO (2011) many risk factors are responsible for chronic respiratory illness, including tobacco consumption, indoor and outdoor air pollution, allergens, and occupational dusts and chemicals. Worldwide, one billion smokers annually consume 6 trillion cigarettes, an estimate that includes commercially produced cigarettes only (thus significantly underestimating overall tobacco consumption, since many smoke hand-rolled, filter-less cigarettes; see Roy 2012); and every year, 6 million deaths occur from tobacco use and exposure (WHO 2011). More than three billion people worldwide rely on solid fuels such as wood, dung, and crop residues for heating and light. These materials cause high levels of indoor air pollution and put members of families, especially children, at high risk of developing respiratory illnesses. Similarly, many environmental and traffic-related circumstances create outdoor air pollution and contribute to the development of COPD and asthma (WHO 2007). Various allergens in the environment such as mites, mould, insects, and pollens may also cause allergic reactions and trigger breathlessness in many individuals. The presence of various organic and inorganic materials in the workplace can create respiratory illnesses in some workers (WHO 2007; WHO 2009b). Medical literatures have also outlined how many environmental factors such as indoor and outdoor air pollution (Yu, et al. 2000; Bush 2001) and the factors of dust and cold

(Weiss, et al. 1984; Milligan, et al. 1998) can cause chronic respiratory illness. These literatures pay minimal attention to the realities of people's social practices (see Wind, et al. 2004). There is also a lack of acknowledgement as to *how* social and structural conditions contribute to people's vulnerability to factors that make them ill (Lupton 1993; Christakis, et al. 1994).

The stories presented above clearly have many overlaps with the discussion in public health and medical literature. For example, the observations of my informants regarding the exacerbation of their illness with exposure to cooking or cigarette smoke, their experience of working for a long time in dusty piles of crops, going fishing on cold winter mornings, and performing household work that required dealing with cold water. The stories of my informants also prove that the underlying conditions associated with such factors were beyond their individual control. Thus, understanding these laypersons' perceptions can greatly contribute towards an enrichment of the public health conceptualisation of the illness (see Popay and Williams 1996).

Chapter Five

Therapeutic Trajectories

Rationalities and boundaries in medication consumption

Sometimes I do not take tablets, I do not take syrups. I do nothing. I just keep quiet. I don't talk. I sit somewhere...or stand still. I try to feel sleepy. I close my eyes...and try not to move.

—Kulsum, 45-year-old housewife.

Amit and I were seated together in my rental apartment in Dhaka. As we spoke about his experience of living with chronic breathlessness, I asked “Why did you consult allopathic doctors?” Amit looked at me with an expression of annoyance. The term “allopathic medicine” refers to modern biomedicine, which is the state-sponsored medical system in the country. Anthropologists have observed the use of various terms such as “modern medicine,” “scientific medicine,” “western medicine,” and “English medicine” that people in different parts of the world regularly use to refer to biomedicine (Leslie 1976: 6). In South Asia, biomedicine is known as allopathic medicine and people often routinely refer to modern pharmaceutical drugs as allopathic medicines in their everyday conversations (Nichter and Nichter 1996). My informants used the terminology of “allopathic medicines” to refer to the modern medical system and also to the biomedical drugs that they obtained from different sources. In Amit’s case, I had noticed that he spoke only of allopathic medicines. When I asked why he went to allopathic practitioner, he thought at first that I was joking. But then he gestured questioningly towards me asking, “What kind of question is that?” Apparently, he considered this question naïve and to some extent insulting. I began to sense that our interview progress was in jeopardy. In order to calm him down, I attempted to turn his attention to the empirical facts of the country: that there were several non-allopathic

practitioners in the area, that different therapeutic systems had been operating for many years, and that many people preferred to consult these practitioners. After I reframed my question in terms of the third-person pronoun, that is, “many people,” it seemed the discussion became re-energised. He zeroed in on my use of “many people”, categorising them as rural “illiterate” people and using negative labelling, and stressing their “low social status.”

Why did he react so strongly to my question? Why did he see the rural people’s use of non-allopathic medicines negatively? How did the rural people themselves perceive their choices of therapies? These are the questions that drive my inquiry in this chapter. The chapter aims to examine the factors that influence informants’ therapeutic experience. It explores the local social contexts arguing that a firm hope for a cure from allopathic medicines motivated informants’ therapeutic decisions. This chapter will explain how this hope is produced and perpetuated in the management of therapy. Even though the discussion starts with Amit-an urban dweller, the central concern of the discussion is not with urban people’s therapeutic experiences. I briefly raise my experiences of speaking with some urban people because their opinions motivated the argument that I want to advance here.

My trip to Dhaka

After a few months in the village in early 2011, my asthma continued to bother me. I usually see my physician once or twice a year to review my asthma. This time, after returning from Sydney, although I had landed in Dhaka as usual, I went to the village straight away instead of staying in Dhaka for a few days. It was harvesting season, and the dust and straw from the paddies were everywhere; this may have exacerbated my asthma. Earlier, I had planned to conduct archival research in some research organisations based in Dhaka. So I thought it would be good to have accommodation of my own there so that I could travel in and out at will. The decision to rent an apartment in Dhaka turned out to be one of the hardest plans to implement. Apparently the problem lay with my marital status. At that time, I was an

unmarried man planning to live on my own in an apartment. The owners were reluctant to rent their apartment to an unmarried man. There were several allegations about unmarried male tenants, including that they could not be relied on to pay rent on time. The most intriguing allegation was that they would attempt to develop love affairs with the landlords' daughters. Such a relationship was seen as wholly undesirable, and would be socially condemned. A friend jokingly commented, "If the landlords hate unmarried men so much, they should not let their daughters marry an unmarried (man) either." After knowing that I was looking for an apartment in Dhaka, the friend said, "[You] rather climb the Everest, and it will be easier [than finding an accommodation in Dhaka]."

Desperate to overcome these obstacles, I decided to try all my options. In contemporary Bangladesh, it is not common practice to place rental advertisements online. Rather, they are posted on streets, usually on electric poles or on the fences of others' houses and shops. Another common practice is to contact friends and acquaintances for information regarding advertisements that s/he may have seen or heard about, an option that seemed like the best choice for me as I was in the village. I called some of my friends and previous colleagues and asked them to spread the message among others. A few weeks later, a friend named Hassan called me on my mobile. Hassan was working for a research organisation based in Dhaka. His employer had transferred him from Dhaka to Khulna, a southern district, for a year. He did not want to move out of his rental apartment in Dhaka as he had faced considerable difficulties acquiring it. He had to bring his mother from his village home to stay with him in Dhaka for a few months to satisfy the apartment owner that he was not going to create "any trouble." It was as if he was being "supervised" by his mother. After a few months, during which Hassan had paid his rent on time and had no issues with the apartment owner, a relationship of trust developed between the two parties. When this trust had been consolidated

by Hassan's friendship with Amit, the younger brother of the owner, his mother returned to the village.

Because he had faced all of these hurdles when attempting to secure an accommodation in Dhaka, he did not think it would be a wise decision to move out of the apartment only to face the same difficulties again on his return a year later. He was looking for someone who needed temporary accommodation, and who would be happy to look after his belongings. The situation seemed perfect for me, and I accepted his offer. After arriving in Dhaka, he took me to see Amit, the brother of the apartment owner, to convince him about this temporary tenant change. Amit, a man in his thirties, was at first not particularly happy after hearing about the temporary change of tenant. With several persuasive requests, and after telling him about my study in Australia for which I was temporarily visiting Bangladesh, he agreed to convince his brother, the owner, about this change of tenants. In our first meeting, I noticed Amit showing particular interest in my study. His mode of inquiry about the possible treatment of chronic breathlessness made me think that he might have a close relative suffering from the illness. The apartment was a two-bedroom unit on the second floor of a five storied building. After I moved in, I met Amit a few times on the stairway. Before long, he invited me to visit his fourth floor apartment.

One Friday, which is the weekend in Bangladesh, he knocked on my door. After exchanging greetings, he invited me to have a cup of tea in a tea stall situated next to the building, a common way of building friendly relationships in Bangladeshi society. As I was busy doing some household cleaning, I invited him to come inside and told him that I would be happy to make tea for the two of us. While we were having our tea, he asked me again about my research. For the first time, he told me about his own breathlessness, which had bothered him for the past ten years. He seemed a little disappointed when he discovered that I neither had medicine to prescribe, nor was I a medical doctor. After I first explained to him

about my study, I asked him if he would like to participate. He indicated his busy schedule and showed interest in talking to me immediately rather than on another occasion.

In Bangladesh, where unemployment and poverty rates are high, Amit's socio-economic circumstances could be considered relatively successful. I met several college graduates who were frustrated either because they were unemployed or under-employed. Amit was running his own business selling imported water filters. After completing twelfth grade, he started working as a sales assistant in a similar water-services company. He worked there for seven years. Later, his brother-in-law helped him with finance to start a business of his own. Since then, he has devoted most of his time to the business. Throughout his working career, he often ignored his doctor's recommendations. For example, his doctor asked him to quit smoking, a request that he could not follow despite several attempts. When meeting with his clients, they would frequently offer him a cigarette, which he felt he had to accept lest his refusal hindered their business relationship. The refusal of a cigarette could possibly appear as the refusal of the collegiality offered by the clients. He also stopped carrying his inhaler at work, as he did not want his clients to know about his illness by seeing the inhaler.

Listening to him, it struck me that he was only relaying his experience with allopathic medicines. Having only just come from the village, I remembered how it was a common practice in the village to try medications from different therapeutic systems. I wanted to know if Amit had also consulted other methods of therapies. When I asked him about this, as I mentioned earlier, he reacted strongly. However, as the discussion went on, I discovered that he had earlier consulted with a spiritual healer who prescribed him a consecrated fish-fry as a therapy for his breathlessness. He "blamed" his grandmother for forcing him to see that healer whom he called "a fraud". When discussing non-allopathic medical system he said,

I simply don't believe this. I have been suffering from this illness for many years, I took so many expensive medicines and saw many famous doctors... still [the illness] does not get

cured... And whoever will come to feed a fish-fry [to cure]! Is it possible? [Laugh] people of [rural] Bangladesh actually are vulnerable to these kinds of people [healer]. If those *kabiraj* (traditional healers) were so powerful, there would not be so many doctors. Many scientists and high-qualified doctors are trying to cure this illness and they cannot. This is just a matter of common-sense that those kinds of fish-fry will not cure this illness. You have to use modern medicine.

I met a few other urban individuals like Amit who consulted non-allopathic medical practitioners but lacked respect towards them, and suggested that the use of allopathic medicine was “a matter of common-sense.” Even my own physician used derogatory terms such as “cheat” and “fraud” when talking to his assistants about traditional medical practice, alerting me to the prevailing status struggle between institutionalised and non-institutionalised medical practices.

After seeing my doctor and purchasing two extra inhalers, I decided to go back to the village as the harvesting activities had already begun. The villagers had told me numerous times how the activities they perform in harvesting time were contributors to their breathing difficulties. I was therefore eager to observe my informants during the harvesting season, and returned to the village as soon as possible..

Back to the village

In chapter 2, I mentioned how the rise in the river water-level, which originates in the high ground and flows through the village lowland region, invariably coincides with the farmers' preparations to harvest their crops. In poor farming families, all family members become involved in the work of harvesting during this critical time. While men undertook a variety of tasks, women mostly worked in the post-harvest stages of work that involved cleaning and drying the crops before storing them at home. The post-cultivation work was usually performed in a *khola*, a specially prepared, cleaned and debris-free section of the rice

field. There were numerous *khola* in and around the village which, needless to say, became inundated with the rise in water-levels.



Picture 9: Villagers working at a *khola*

One day, when I was passing one of these *khola*, I met Kulsum, a forty-five year-old housewife. I saw her busily winnowing to filter straws from the paddy. She was using the wind to blow away the straws. I noted that she repeatedly rested in the bamboo tent in the field. I found out that she came to the *khola* to help her husband process the paddy, as they did not have enough money to hire an extra labourer. I watched as she repeatedly rested. She was wheezing too heavily to be able to keep up with the work. Later, I met with Kulsum at her house, and also returned to visit her a few other times. During these visits, she told me of her experience of using different therapeutic options to deal with her wheezing, from which she has suffered over the past ten years.



Picture 10: Winnowing crops

Although Kulsum had tried different therapies for her illness, at the time of the interview she was using allopathic medicine which she received from a village medical practitioner. She told me that she would not seek any other assistance but allopathic medicine. Having earlier noted Amit's firmness of decision regarding allopathic medicine, I was interested to see if I could detect similar faith in Kulsum. I soon discovered that her support for allopathic medicine was rooted in her subjective notion of the efficacy of medicine. She said:

I had a tumour in my belly... like a small piece of soap. I tried allopathic medicine [from the village practitioner] for three years. Later I tried homeopathy too. In the end, the homeopathy doctor told me that homeopath or allopath would not work and said, "You should try Bengali medicine." Then I stopped everything and just kept eating [taking] Bengali [medicine].¹⁰

Within a few years of having Bengali medicines, the tumour was finally gone. In this way, I

¹⁰ According to my informants, traditional healers (*kabiraj*) prepare *Bengali* medicines from several vegetation and herbal elements.

tried Bengali medicines for my breathing difficulties too, but they do not work. Allopathic medicines work...

According to Kulsum, her breathing difficulty was an illness that required a quick remedy. She said that it was not possible for her to wait to see the results after therapy was administered. She stated that allopathic medicine worked faster than other medicines. She also told me about her initial experiences of how she had stopped using allopathic medicine, even though they brought faster relief than other medications. She discovered that the medications had only brought temporary relief. She had a suspicion that the allopathic medicine might have been “suppressing the illness inside her body and stopping her to get rid of the illness.” So she stopped the medicines. Later, she travelled to several remote villages to consult famous traditional healers (*kabiraj*). In addition to drinking various specially-made herbal syrups she obtained from them, she had also used a consecrated thread, and maintained various diets as instructed.

Despite all these efforts, she felt only minimal relief from her wheezing. Her experiences with non-allopathic therapies were not as satisfactory as she thought they would be, so she decided to switch back to allopathic medicine. She commented, “I will not seek other (therapeutic) treatment, if it gets cured it will be cured by allopathic, otherwise it won’t.” I observed this faith in and strong support for allopathic medicine in all of my informants. While their faith was supported by their subjective notions of efficacy, their understanding of the severity of the illness probably also influenced their opinions.

For example, Mosharrof, a man in his fifties said, “If it is an umbilicus disease, would that be cured with a consecrated thread?”¹¹ His use of the term “umbilicus disease” was not a reference to an illness of the umbilical cord *per se*. Rather, by deploying this term he was

¹¹ *Rog hoile nare, suta-natay chare?*

referring to the severity of the illness. An umbilical cord connects the foetus to its mother and plays a critical role in the development of unborn child. Any illness (problem) in that cord may endanger the life of the foetus. Likewise, his metaphoric use of “umbilicus disease” was in reference to the “deepness” and severity of chronic breathlessness. When I asked him about his perceptions of “deep illness” he listed heart disease, breathlessness, and cancer, arguing that these “deep illnesses” should not be treated with non-allopathic medicine.

I noted a distinctive difference between the rural informants’ faith in allopathic medicine when compared to the perceptions of their urban counterparts. The disdain displayed by urban informants when they spoke of non-allopathic medicine seemed rather ironic, especially given that most of them had used these therapies themselves. Although it is tempting to interpret their position as a form of self-deception, I consider it to be a manifestation of the extant interaction between modernisation and allopathic medicine. While listening to Amit, I wondered about the extent to which his firm support for allopathic medicine was rooted in his subjective notion of efficacy, or the extent to which it could be attributed to the status of allopathic medicine in Bangladeshi society. As a form of modern medicine rooted in a scientific epistemology, allopathic medicine holds considerably higher status, at least in urban settings, than forms of non-allopathic medicine (Leslie 1976; Lock and Gordon 1988). Given Amit’s reference to “illiterate villagers,” which signified a marginalised socio-economic group of people who were “unable to realise the potential” of allopathic medicine, it seems likely that his criticisms of non-allopathic medicine lay with a question of status rather than some personal notions of efficacy.

Amit’s opinions did not just demonstrate his perceptions regarding rural sufferers of breathlessness. His strong views on non-allopathic medicine also indicated his personal ideals and his attempts to claim higher social-status by referring to his choice of therapy. In this context, the use of allopathic medicine was not only a therapeutic system; it was a cultural

system, a symbol of modernity that incorporated several aspects; for example, high economic status and literacy, social class, and the overall habitus of the speaker (Bourdieu 1984; Ram 2010). Being able to live in an expensive city like Dhaka, unaffordable for many rural villagers, and having access to education in a highly stratified society are incorporated into the mindset of urban informants like Amit as symbols of modernity. For them, the use of and faith in allopathic medicine, attributable to its connections with modernity, became “a matter of common-sense.”

By contrast, the rural sufferers appeared to adopt a more nuanced approach when expressing their supports for allopathic medicines. Although some tried different therapeutic systems during their search for a cure for their breathlessness, they were candid about their “trial and error” approach. Their attempts were self-explanatory and rooted in a subjective notion of therapeutic efficacy as opposed to the existing status-quo of different therapies. In other words, choosing allopathic medicine was not a matter of a blanket preference, or faith in one system or another. Instead, the decisions of rural sufferers about where to seek treatment, was based on pragmatic considerations of their complaints. And yet, despite their seemingly sensible support for allopathic medicine, my rural informants were not free from the pervasive aura of allopathic medicine in terms of its triumphant and heroic image in the area.

The image of allopathic medicine

A hero is someone who is unbeatable, someone who has tremendous ability to conquer any battle. I observed this metaphor of heroics surrounding allopathic medicine, especially when my informants spoke of success stories when other illnesses they suffered had been cured. My first meeting with Komol, an elderly male sufferer and a friend of my research assistant Salil’s father, helped me to discover how a success story of an illness may contribute towards a triumphant image of certain medical system.

A few years ago, when Komol was diagnosed with tuberculosis, he was terrified. He thought that he might die at any time. For several months he had suffered from coughing. Although he continued to take medication prescribed by the village practitioners, he did not experience any substantial improvement. At some point, one practitioner suggested he should go to the nearest sub-district healthcare centre, to have his cough tested for tuberculosis. This suggestion disturbed him and he became scared. Earlier he had watched several advertisements on television about tuberculosis. The advertisements stated that anyone who had a cough for longer than three weeks should be tested for tuberculosis. Although the advertisements stressed that tuberculosis was a curable disease, he never entirely believed them. Since childhood he had known how fatal this illness could be. He knew that he could easily die from tuberculosis.

When the rural practitioner suggested he should have his cough tested, for the first time, with all his heart, he wanted to believe that the information in the advertisements was correct regarding curability. The cough test revealed that Komol was indeed suffering from tuberculosis. He was told that if he came to the healthcare centre every day to take the free medicines, he would be cured.¹² After asking Komol to do this many times, the staff at the health centre came to realise that it was not possible for him to travel to the centre every day. Although the medicine was free, the transport cost and the time for travelling was simply impractical for him. Accordingly, he was asked to come just once a week, so as to collect the medicines for the next week. He continued his medications for six months, taking extreme caution.

¹² Tuberculosis control program in Bangladesh is delivered through several governmental and nongovernmental organisations. Following DOTS (Direct Observed Treatment Short course) they provide treatment where individuals have to take their medications in front of a staff member. One of the reasons for this method was to avoid Multi Drug Resistant Tuberculosis (MDR TB). My experience with one of the NGOs that offered treatment for tuberculosis taught me that the centres in remote areas did not always have trained medical doctors for diagnosing and providing treatment. Rather some trained technicians implement the project. And in many cases, the staffs accommodated the treatment plan according to the circumstances of the sufferers rather than strictly adhering to the DOTS programme.

At the end of the treatment regime, he was tested again, and found to be free from tuberculosis. With this news, he experienced great relief knowing that he was not going die from the disease. Unfortunately, only a few months after recovering from tuberculosis, his wheezing began. Difficulty in breathing disturbed his sleep. He became frightened that he might have caught tuberculosis again. This time, he wasted no time in heading to the healthcare centre in the sub-district to have his cough tested. The staff said that he no longer had tuberculosis and suggested that he should see a doctor who specialised in *hapani* (chronic breathlessness).

In Bangladeshi society, because of strong stigma associated with tuberculosis (Karim, et al. 2007), individuals go to great lengths to avoid an infected person. When a person in a family is diagnosed with this illness, s/he may be subjected to a form of social exclusion; that is, the illness may encourage separations in familial and social relations and/or hamper potential marriage prospects. A local proverb “*jokkha hoile rokkha nai*” suggests that there would be no other way (but to die) if someone is infected with tuberculosis. This saying was so ubiquitous that the national tuberculosis control program had to invent a new version of it to convey that the illness was curable. Tuberculosis, as I observed during my fieldwork in 2010, was generally perceived to be more deadly than breathlessness. Yet I also felt a new sense of certainty among people that tuberculosis was curable. Apu and Komol’s verbal and non-verbal modes of describing their experience with tuberculosis, for example, reflected these fluctuating perceptions very well. It is likely that such changes in people’s perceptions have occurred because of the extensive public health campaigns.

Although Komol described tuberculosis as something that potentially could kill him, he expressed a deep satisfaction about the cure. I sensed a degree of certainty when we discussed his diagnosis and treatment for tuberculosis during the interview. Several times he emphasised that his cough was *tested* for tuberculosis. The medical staff had assured him that

six months on medication would *cure* the illness. And finally, another *test* had revealed the cure. His awareness of numerous advertisements about the curability of tuberculosis may have also reinforced this sense of certainty. In other words, the constant spread of information about a cure, along with individuals' positive outcomes of the treatment, have transformed an illness that was historically perceived to be fatal into a treatable, less-fatal illness, a transformation that I also observed during another study (Roy 2012). This shift in the perception of an illness – in this case tuberculosis - also speaks *for* allopathic medicine and the processes involved as part of this system of medicine. Such processes include the administration of diagnostic tests, prescriptions, the use of medication in keeping with a specified time-frame, and follow-up diagnostic testing to ensure a cure. This instrumental trajectory, combined with widespread promotional activities of public health campaigns has contributed to the development of the triumphant image of allopathic medicine where tuberculosis and other diseases are concerned.

During my fieldwork, I became aware that urban medical representatives were paying regular visits to the rural areas in order to promote the allopathic medications that their companies produced. Medical representatives distributed countless pamphlets and leaflets and hung many posters advertising their company's medications throughout the village bazaar. In addition, they arranged formal sessions with rural medical practitioners, which they referred to as "conferences," to "discuss" their products (medicines). Through these sessions, they "taught" the rural practitioners about their medications, their specified dosage, and the possible symptoms for which they should be applied as treatment. In my observations of these conferences, I noticed the medical representatives were incredibly persuasive in their interactions with the rural medical practitioners. The representatives would convincingly explain the clinical efficacies of the drug, and reinforce the reputation of the pharmaceutical company in an effort to add symbolic power to their company's medications and motivate the

rural practitioners (I describe the activities of these drug representatives in more detail in Chapter 6). It is not unlikely that this powerful image of the (allopathic) medications, along with several posters and leaflets, may have later been transferred to the villagers through their numerous interactions with the rural practitioners.



Picture 11: An ad of an urban physician from another district

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Santi Rozario (2002a) has rightly observed that Bangladeshi villages are no longer isolated from urban centres due to several interventions from government and non-government organisations. One cannot ignore the impact of these interventions on health issues (primary healthcare for example) in the local people's perception of medications. Scholars have described how health interventions such as the immunisation of children have played a dramatic role in combating infectious diseases in Bangladesh and in many other parts

of the world (Cockburn 1963; Perry 2000). The dramatic changes in various known causes of mortality and morbidity thus may also have contributed to the local people's perceptions of the efficacy of allopathic medicine. I met some elderly villagers who told me how in the past, diseases such as cholera were fatal when they were young. They described how village after village had encountered widespread deaths from cholera, and that the low incidence of cholera today was due to the use of allopathic medicines to treat this disease. My findings here are in keeping with the observations of other anthropologists regarding the transmission of an epic image of allopathic medicine. Gaines (Gaines 1992b in Gaines and Davis-Floyd 2004) describes this process of transmission as something that is learned and shared in several ways such as through communications between individuals, as well as through various texts and images in both electronic and print media. My prior discussion shows the presence of both these avenues at work in the transmission of an epic image of allopathic medicine into the villagers' minds.

In sum, there was perception among people in the village that allopathic medicine was capable of permanently curing diseases previously seen as incurable, or responsible for stigma, social ostracism, and high mortality rates. This perception of the curing power of allopathic medicine, however, did not extend to the chronic breathlessness of my informants. The remainder of this chapter deals with how this image of allopathic medicine has shaped the therapeutic trajectories of my informants.

Seeking medical assistance

Sukesh was a twenty-eight year-old farmer who worked on people's lands on a yearly contract basis. This type of contract usually ended at the completion of the harvest, when the farmer received his annual remuneration. As a farming labourer, Sukesh performed all the tasks relating to cultivation including ploughing the land, preparing the seedbed, sewing the

seedbed into the ploughed land, ensuring sufficient irrigation, using fertilisers on time, taking cautionary steps such as building fences to save crops from being devoured or trampled by cows and other animals, and, in the harvesting season, cutting the crops with a machete. The landlord provided limited financial support, such as for the cost of fertilizer, and usually expected everything to be completed in a timely manner. Although these responsibilities were rigorous, they were regular parts of Sukesh's life until he succumbed to breathing difficulties.

Sukesh's life altered dramatically when breathlessness caused him to lose his regular job. Though this happened four years ago, the experience remained vivid in his memory. He had worked for this particular landlord for many years. Each year the landlord had renewed his contract following a review of his performance. After working with the landlord for such a long time, Sukesh came to feel that he was part of the landlord's family. Then one day, when he was ploughing the land using an oxen-drawn plough, he felt that he could not exhale properly. As they moved through the sludgy land, it became harder and harder for him to keep up with the oxen. As they traversed the land from one side to the other, he felt as though he was panting. Finally, he felt so weak that he had to stop ploughing and he sat down to rest in the middle of the paddock. Because he could not finish ploughing that day, it took him more than two weeks to finish that small part of the land. The landlord noticed that he was not finishing everyday tasks as instructed. A few weeks later, the landlord gave him one hundred taka (\$1.40) and told him to go home and take a "rest." He complied with the landlord's suggestion saying that he would take medicine, and would soon be cured. He promised to resume work as soon as he was able. The landlord, however, informed him that it was not possible to leave the land half-ploughed and he would have to hire other people. This was how Sukesh lost his regular job contract.

His wife gave him a hot oil massage on his chest for a few days. They both believed that this massage would remove "the cold" from his chest. He also went to visit a local healer,

who instructed him to wear a consecrated thread around his neck. From the very beginning, his wife kept asking him to see a “doctor” (village medical practitioner) in the bazaar. But since losing his job, he was reliant on borrowed money and did not want to “waste” money on expensive allopathic medicine. Instead, he decided to try some traditional healing and home remedies in the hope that they would bring a cure. However, these remedies did not bring any substantial improvement. In fact, he realised that his wheezing was becoming worse, particularly at night. His wife became extremely worried. She cried and begged him to see a “doctor.” She even gave him some money from a loan that she had taken from a local NGO to start a small shop of selling candy and biscuits at home. At last, he consulted a local practitioner in the village bazaar. As the days passed by, he became more and more frustrated that the medicines from the local practitioners were not curing his wheezing permanently. They only brought temporary relief.

He discovered that his breathlessness was manageable if he did not work in paddy fields, stayed out of the sun, and did not spend long periods of time in the wet sludge. But these were precisely the tasks that he must perform to work as a farmer. Frustrated, he commented: “This is an illness of happy people.... you cannot do any work. You just sit back and relax.” His expression “happy people” connotes the material abundance of one’s life. It was a common perception amongst most of the villagers that rich people were the *happiest* people, as they did not have to work hard in the rice fields the way poor farmers and labourers did. Having an illness that required Sukesh to stop doing what he was supposed to do for a living metaphorically appeared to him as an illness of rich (happy) people.

The story of Sukesh suggests that seeking medical assistance may not be always a straightforward decision. Many complexities may surround the decision to seek medical help. In order to understand these complexities, it is imperative to explore the background of his suffering. Sukesh’s comment, “This [breathlessness] is a happy illness, [which] I cannot

afford to have” reflects his frustration, which is attributable to the abject poverty that determines his life and his disappointment about his job loss. Irving Zola (1980) rightly observes that individuals with illnesses should not be seen as “willing supplicants, rushing with open arms to seek aid”. Rather, he says, it takes “a quite complex set of social events” to make individuals consult medical practitioners (Zola 1980: 241). Nevertheless, it remains the case that sometimes, even where there are overwhelming obstacles such as poverty and unemployment, people do seek out allopathic medicine to treat chronic illness. For the purposes of this chapter, I am interested in how people experience the use of medication under such circumstances, particularly given that treatment is essentially continuous in nature.

In the following section, I discuss the therapeutic experience of Kulsum, a female sufferer whom I have introduced previously. Her story sheds light on the complex interactions between the roles of rural practitioners, prescribed therapies, socio-economic incapacities, and the socio-cultural meaning of breathlessness.

Therapeutic experience

It started 8 or 9 years ago. I did not have this illness before. It started with mild cough. I had accompanied the wife of Khalek a few times to Mohongonj and the bazaar [to take her to medical practitioners] and suddenly I got this illness.

In this interview excerpt, Kulsum was telling me of her initial experience of breathlessness. At the time, she lived in a section called the *shibir* (The camp) in a corner of the village. Khalek and his wife, whom she refers to in her narrative of this pivotal moment, were her next-door neighbours. Kulsum’s husband, Jamal, and Khalek worked as farmers for a rich landlord. Since both men left for work early in the morning, they developed a strong friendship. Similarly, a close relationship developed between Kulsum and Khalek’s wife Rabeya.

Kulsum suspected that her own breathlessness might be linked to her companionship with Rabeya, who also suffered from breathlessness. The two housewives became so close that they used to exchange any special foodstuffs they had cooked, a form of showing affection and care that was common practice among women in the village. Kulsum, as the younger of the two, addressed Rabeya as *bubu*, a typical kin term extended to “elder sister” in the community. Kulsum became very sad when she became aware of her “sister” Rabeya’s breathlessness. Khalek did not arrive home until late at night. Kulsum was unable to rest when she saw Rabeya crying and suffering every time she tried to “take a bit of an air.” Several times she took Rabeya to the medical practitioners in the village bazaar. She also accompanied her to Mohanganj (a nearby sub-district), a journey that took half a day, to see a physician. After discovering her breathlessness, Kulsum started spending less time with Rabeya.

Like many others, Kulsum had tried some home remedies such as hot oil and mashed garlic massage on her chest, and bathing in hot water for a few days. Later, she thought that she must need “a good cough syrup” from the bazaar. But she was worried about the cost of seeing a practitioner in the bazaar. She also worried about whether the practitioner would prescribe several medications, because if this happened, she would not be able to afford the cost at all. Her husband suggested that she should try a *kabiraj* (traditional healer) in their village. They knew that a *kabiraj* would cost only one pot of rice, a common currency of barter used in small transactions in the village.

Although the medicine Kulsum obtained from *kabiraj* had an “awful taste” and made her vomit a few times, she continued the regimen for a week. Still, she kept thinking that she should have gone to the allopathic practitioner in the bazaar rather than consulting a traditional healer. Some neighbours also suggested homeopathic medicine, which was cheaper than allopathic medication. Since she considered homeopathy “a slow medicine” that “took

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forever” to take effect, she opted against it. But soon she noted deterioration in her condition, and wheezing became worse. Often she would awake in the middle of the night gasping for breath. Sometimes she would sit up in bed the whole night until *fazar aazan* (early morning Muslim prayer time). Finally, setting the worry of money aside, she decided to see Subash, a practitioner in the village bazaar.

Subash, a self-taught practitioner of allopathic medicine and Kulsum’s regular doctor, allowed her to pay the cost of her medicine in instalments. When treating her breathlessness, he initially gave her a cough syrup and some tablets. She immediately felt much better. Then, she decided to try taking the tablet and the syrup separately, to find out which one was the less effective. She discovered that the syrup was more effective than the tablets. So she decided to return the rest of the tablets to reduce the amount of money that she owed to Subash. At first, she was satisfied with the price and outcome of the syrup (Butol[®]). Before long, however, her satisfaction turned into a nightmare when her hands began to shake constantly.

Although her wheezing had lessened since taking the syrup, Kulsum had begun to feel indescribably weak. And when the shaking began, this weakness became particularly acute. She even lacked the strength to perform her household work properly. Not knowing what was going on, she rushed to Rabeya for advice. Rabeya told her that she had also experienced weakness and constant shaking after taking Butol[®], and that these were simply “side effects of the syrup”. Rabeya explained to Kulsum that she was becoming weak because the syrup was “eating up all the calcium” of her bones and that is why she was becoming weak¹³. After discovering this “fact” about the syrup, Kulsum stopped drinking it. Within few days of stopping the syrup, her wheezing and restless nights returned, prompting her to consult Subash again.

¹³ When I questioned her about calcium, she told: “Are there not salt-and-water in the bones? This syrup takes them out of the bone and makes you weak...”

Kulsum was angry with Subash because he had prescribed “the harmful syrup.” She wanted to scold him for draining the calcium out of her bones, for making her weak. However, she controlled herself and spoke to him about it softly. But, instead of apologizing to Kulsum, Subash became angry, saying that the “better” treatment for breathlessness was so expensive that she would not be able to afford it. He also said that Butol[®] was the best solution for her. Kulsum was afraid to ask him any further questions. She worried that if he became angry, he would not allow her to pay in instalments and some of her payments were already overdue. Subash also told her that if she did not want the side effects, she could have injections. But these injections were to be administered only when the breathlessness was severe. In this way, Subash told her, the illness could be “gradually killed from the root.” Kulsum claimed that taking injections gave her a “death-like feeling”:

When Subash administers injection.... It is terrible...He would hold your hand so strongly and pushes the injection which hurts excessively... [She was showing her chest (heart) and saying that she felt she would die]. I have to breathe like this [showing how she inhales through mouth with keeping it wide open], I cannot breathe. The way he pushes injection, it just directly [strongly] attacks the *kolija* [showing the chest (heart)]. It won't take long for people to die at his hand. I feel I will die [at his hand].

At the same time, Kulsum described to me that she found this “death-like injection” administered by Subash effective.

It is likely that the pain and death-like experience in this process have contributed to the perceptions of efficacies (for a discussion on culture and efficacies, see Etkins 1988; Etkins 1992). Once Kulsum decided to see another self-taught practitioner, Aise, whom she believed had a special skill in administering painless injections. She took an empty vial to Aise to show him the name of the injection. Although she found the actual injection considerably less painful than those administered by Subash, she described the outcome as “hopeless.” She felt that the injection administered by Aise was not effective enough to stop

her wheezing. She believed that Subash's hands had some very special power (*hater gun*) enabling him to give an effective injection, something that Aise lacked.

Anthropologists, writing about the symbolic power of medicines, have suggested that perceptions of the "power of the hand" may influence choices about which practitioner to consult for particular ailments (Van der Geest and Whyte 1988; Nichter 1996; Whyte, et al. 2003). This notion of the "power of the hand", as Nichter (1996) observed in South India, was typically associated with a story of a serious illness that was cured by a certain practitioner, an illness that at least one other practitioner had failed to cure. This resulted in the development of a perception that the successful practitioner's hands possessed a special kind of power that could heal a particular illness, or heal a particular age group of sufferers.

When Kulsum discovered that Subash's injection was more effective, she returned to visit him again. She described the symptoms that prompted her to visit Subash:

...the back ache starts and I know it is coming... The breath (*dom*) does not go down; it just wants to go up. It [wheezing] makes scary sound. It just wants to go up. It is not possible to eat any food at that time. Whenever I get this [emergency] situation, hurriedly I run to Subash [to get the injection]. As soon as the injection is done, everything (breathing problem and associated ailments) becomes cold (calm).

After receiving the injection, she would pay him whatever money she had brought with her and request that he keep a note of the remainder owed. Kulsum would then clear all of the accumulated debt in *Boishakh*, the first month of the Bengali calendar and a month in the harvesting season. In *Boishakh*, they would harvest the crops from the small amount of land that her husband cultivated. In addition, Kulsum's husband would also get the yearly remuneration from the landlord in *Boishakh*. Then, Kulsum would pay off all the debts that had accumulated throughout the year, including debts with grocery shops, the medical practitioner, and others.

Sometimes, Subash would behave poorly and demand money before the harvesting season arrived. When this happened, Kulsum would try various sources to get some money to pay at least a small amount to placate him. On one occasion, Subash announced that he would not give Kulsum her injection unless she paid her debt. He was adamant, denying her repeated pleas. She promised him to give some money if he gave her the injection. After returning home, she sold one of her two hens, which she kept as domestic animals, to clear part of her accumulated debt.

Despite all these adversities, Kulsum was not able to give up the syrup. Initially she was very happy to be rid of “the bone-eating syrup”, but she soon realised she was wrong. Although the injections reduced the extreme wheezing and prolonged the time before the next severe attack, Kulsum was not completely free from wheezing during the interim period. She still occasionally experienced shortness of breath and disruptions to her sleep. Subash told her to take the tablets that he had prescribed earlier but she found “the tablets were bringing water” in her hands and legs and making them swell.¹⁴ She felt weak again.

Seeing no other way out, Kulsum went to see Subash again. He told her that she had only two options left: she could either take the Butol[®] syrup again or start using an inhaler. Kulsum refused to use the inhaler. Although extremely anxious, she had started to take “the bone-eating syrup” again in the period between the two injections so Subash advised her to take some calcium tablets to compensate for the bone-density loss. He also suggested that she eat good nutritious food on a regular basis. Kulsum could not afford the calcium tablets, so she decided to eat eggs and meat and to drink milk.¹⁵ Due to her poverty, however, she could not keep up this diet for long. She resorted instead to another strategy, and became more

¹⁴ *Ei bori khailey hato pauo fani aiya fore, hat pa fuila jay*

¹⁵ Culturally, eggs, meat and milk are thought to be nutritious food items in the village.

careful in her use of the syrup. She tried to minimise the perceived harmful effects of the syrup on her bones by drinking as little as possible. Instead of taking a sip whenever she was wheezy, she would wait until the moment when she could not wait any more.

I was curious to know why she refused the inhaler and chose the syrup, something she considered harmful. Initially, I presumed that the price of an inhaler could be behind her decision, as it was unaffordable for many rural villagers. The price of Brodil[®], a Salbutamol inhaler sold in the village bazaar, was fifteen times higher than Butol[®], the syrup of choice among sufferers and the one used by Kulsum. When I asked Kulsum about her preference for the syrup, she did mention the high price of the inhaler. However, I was not completely satisfied with her response. I had noticed many other sufferers also showed a tendency to avoid the inhaler as a form of medication to manage their breathlessness. I also knew that many of these sufferers were perfectly able to afford the price of an inhaler. Thus, when Kulsum told me that her refusal to use the inhaler was because of the high price, I decided to probe further.

As the interview progressed, I discovered that one's choice of therapies – whether someone uses an inhaler, for instance - may influence how others perceive the severity of an individual's breathlessness. This became evident during our discussion when Kulsum compared her own breathlessness with that of her neighbour, Rabeya's breathlessness, as a means of illustrating for me that her own breathlessness was not "severe". She said, "She (Rabeya) uses those things (inhalers)... but I do not (stress in tone) *need* them." In this way, the use of an inhaler was an indicator of the degree of severity of one's breathlessness. The fact that Rabeya used an inhaler marked her illness as more severe than the breathlessness suffered by Kulsum. Social stigmas may also play a role here. As I discussed in chapter 3, many sufferers of chronic breathlessness depict their illness as less-fearful or less-severe in order to combat stigma. Therefore, avoiding the use of an inhaler may be one way that

individuals seek to lessen the visibility of their illness, and deflect the stigma attached to breathlessness.

Most of my informants labelled the use of inhalers as “the last treatment” and thus considered it an undesirable therapeutic option. Several times, informants told me that people should not use inhalers unless they had no other way to manage their breathlessness. They suggested that once someone began using an inhaler, there was “no hope” of curing the illness. This, they reasoned, was because people became “dependent on inhalers.” At the same time, sufferers avoided homeopathic and other non-allopathic medicines because they were “slow” therapies. They wanted “quick” therapies, i.e., allopathic medicine. Ironically, the reason for rejecting inhalers was that inhalers provided a quick (temporary) fix of breathlessness as opposed to a stable or permanent cure. There were several metaphors in the informants’ discussion of inhaler use. Uttam, a middle aged man, told me, “Inhaler works like current [electricity], you use inhaler, and everything is clear straightaway.... Just like you press a switch and light is on.” This metaphor may have derived from his everyday experience of living with electricity disruptions several times a day. Bangladeshis do not usually receive any prior notices about electricity disruptions. However, even if the light was quickly turned on after the electricity resumed, it could be gone (off) at any time. In other words, the unexpectedness that was associated with the disruptions in electricity marked the unexpectedness associated with the experience of breathlessness. Thus, for Uttam, the inhaler appeared as a quick temporary fix.

The quick fix associated with an inhaler was viewed so negatively that the informants opted to use it as little as possible. An elderly sufferer called his inhaler “the medicine of death” (*moroner oshudh*). He believed that the strength of the inhaler was making his body weaker, and rendering other “normal medicines” such as tablets and syrup ineffective. He observed that he previously used one inhaler for more than a month; but, at the time of the

interview, one inhaler was lasting no more than two weeks. He said that it was the inhaler that was “taking him near to death,” slowly reducing his breathing capacity. He was so upset about the poor prognosis of his breathlessness that he said, “Because of this inhaler...my vessel is near to the shore... no point in trying to save it from sinking [now].” Notably, such frustration and disappointment were not exclusive to those informants who used inhalers. Rather, it was a common feature among most of my informants, irrespective of the types of medication they were taking.

Disappointment

On the day before one of our meetings, Kulsum went to bathe in the river next to the village. She preferred to take a shower by sinking her head into the water. Suddenly, while she was in the water, her wheezing started. She struggled to draw her head up out of the water. Although she was a good swimmer, she found herself fighting in the water for quite a few minutes before she was finally able to get back to the bank. She rushed back to her house as quickly as she could, changed her clothing and went to see Subash. The road to the bazaar seemed so long to her. She was short of breath after every few steps, and was forced to sit resting in the middle of the muddy path a number of times. When she reached his dispensary, Subash was not there. He had gone home for lunch.

Kulsum became increasingly frightened. Struggling to breathe, she waited nearly an hour for Subash to return. She thought this was the last moment of her life. She relayed this event to me as an example of her ongoing frustration and disappointment surrounding the unexpectedness of her illness. Despite going through numerous painful experiences of injections, and after emptying several bottles of “bone-eroding syrup,” she was extremely disappointed that she was not achieving a permanent cure. As her debt to Subash increased,

and her ability to perform everyday household chores diminished, she became more and more frustrated.

Because of her wheezing, Kulsum struggled to carry *kolsi* (a local water carrying pot). She sensed that she was gradually losing her energy. She was unable to adequately support her husband in their cultivation work. Although her husband took care of all of the cultivation activities in the field, she was responsible for many tasks when processing the crops during the cultivation period. She had to help with the post-cultivation processing. She would wash the rice and guard it from animals and thieves while it lay in the sun drying. Later, she would pour the rice into rucksacks before taking it home. However, performing these tasks had become a constant struggle because of the poor effects of the medicines, and the unexpected contingencies surrounding the attacks of illness.

When Kulsum's only son left home after his marriage, and stopped providing any financial support, her life became even more difficult. While they waited to receive harvested crops, the family was forced to run mostly on credit. Because of this, a large part of their yearly income was spent repaying their debts, meaning they were unable to generate any surplus earnings. Without any extra money to hire a maid to help with everyday household activities, Kulsum could not afford to be sick even for a day.

Like Kulsum, most of my informants were clearly disappointed with the temporary effectiveness of their medications. In the initial stage of medication use, many stopped taking their medicine, thinking that they were cured. Disappointment soon engulfed them, however, as their wheezing returned within a few days. Poverty further enhanced these frustrations, as they were often forced to borrow money from their neighbours, or sell their belongings to cover the cost of their medications. Even though self-taught practitioners in the area did not charge a consultation fee and transportation costs to see them were negligible, these sufferers

continued to struggle to gather enough money to visit them, a situation that reflected their extreme socio-economic marginalisation. And yet, most of my informants continued their prescribed therapy on a regular basis for a certain period of time (which varied from one individual to another) even when they had varied perceptions of the efficacy of these therapies. Under the circumstances described above, it is likely that the heroic image of allopathic medicine motivated their usage of medications. In the following section, I describe how informants have used the same heroic image of allopathic medicine to justify the perceived inefficacy of the medications that they obtained from the local practitioners.

Hope is out there

During my stay in the village, as I mentioned in chapter 2, I observed two completely different landscapes in the area. In rainy season, all open fields were inundated and water was everywhere. The villages looked like small islands bounded by water. Conversely, in the dry season, all the rice fields emerged from the water and became dry again. At this time of year, the farmers were busy preparing the fields for cultivation. The only river, earlier the source of an abundance of water, now became a narrow, long canal due to the extraordinary dryness. It was on one of these dry days that my research assistant, Salil, and I walked for more than an hour to meet an elderly female sufferer named Fulbanu. On this journey, we crossed two bridges made of bamboo that spanned two small estuaries. Walking on six-inch wide bridges entailed a precise and cautious balancing act.



Picture 12: A bamboo bridge

The small hut in which Fulbanu lived was made of straw, bamboo strips, and old plastic bags. An old plastic tarp over the bamboo roof was held down by some debris stacked on top to stop the wind from blowing it away. Stepping in from outside, the room seemed dark. The only window provided little light even though it was noon and the sun was bright outside. We were immediately struck by the foul smell of human excreta. I asked Salil to wait outside. I saw the impoverished Fulbanu lying on a makeshift wooden bed made of small pieces of used timber. The alarmingly rapid rise and fall of her chest was the first thing I noticed when I saw her. She was fighting to breathe by keeping her mouth wide open. To me, these seemed the only evidence of the presence of life.

Although I was not a medical doctor, I was quite certain that she was suffering from more than just chronic breathlessness. Her emaciated body showed signs of chronic malnutrition. Old age may have escalated her weakness though it was apparent that her

greatest difficulty was that she was panting for breath. While she lay motionless on the bed, she stared at me with absolute distress in her eyes. I immediately decided not to bother her by asking any research questions as I felt this would only increase her wheezing.

Rahela, her daughter-in-law, entered the room. She said that “too much movement” was making Fulbanu breathless. For this reason, she tried not to move “too much” and spent most of her time in bed. Sometimes her situation would worsen to the extent that for several days on end she was unable to eat even a child-size meal, as any attempt to eat would make her breathless. She was often unable to get up and walk to the toilet outside, having no option but to defecate in a plastic pot.

Rahela had witnessed Fulbanu’s breathing difficulty since she came to the family as a newly married bride twenty years earlier. Over the past five years, the family’s situation had deteriorated. Rahela’s husband, who was Fulbanu’s only son, was a fisherman. He worked constantly, managing to earn 200 to 300 taka (\$3 to \$4) per day. His meagre income was under threat as big businessmen had leased a vast area of the river and banned the local fishermen from fishing there. Despite his scant and unstable income, whenever Fulbanu’s situation worsened he would run to the medical practitioners in the bazaar to get medication, usually a bottle of Butol[®]. The extreme poverty endured by the family forced Fulbanu to learn to cope with her illness in a strange way. She developed special positioning of her body in the bed that gave her a little comfort when she was wheezing. Rahela, describing these techniques, said that Fulbanu slept with her body in a circular position, keeping her knees near her chin. Sometimes, she would just keep her body straight and stare at the roof without moving. Expressing her frustration about the way Fulbanu’s breathlessness was managed, Rahela said,

Only if we can get *real* treatment, then it will be cured. How do we get so much money? If we only take her to Netrakona [district town], at least four to five thousand taka is needed.

Without a big doctor and proper examination, it will not be cured. Only proper examination can reveal the root of this disease.

Clearly, Rahela believed that treatment from formal physicians in the city would cure Fulbanu's illness. In the middle of our discussion, a neighbouring woman named Salma arrived and began telling us about her seven-year-old son's breathing difficulties. I realised that she thought I was a doctor or a community health worker. To my surprise, even when I interrupted her to explain my research project, she did not pay any attention to what I was saying. Her reaction made me think that she had not understood my explanation and I was reminded of how strongly Bangladeshis linked anyone studying health or illness to biomedical institutions. It was as if anyone interested in health and illness must be a health worker, or a trained doctor. In order to distinguish my role as a researcher from that of a medical doctor, I went on to explain my role in terms of the local category of "surveyor". This explanation brought about an expression of frustration as her hopes of attaining medical assistance faded instantly. Even so, when I asked her to tell me about her son's illness again, she agreed to talk.

I did not ask Salma to accompany me to some private place to talk. My fieldwork experience had already taught me that any attempt to implement Western notions of privacy were counterproductive. The villagers lived in a context wherein everyone knew each other. Interruptions by others, depending upon the mode of address, were often considered to be expressions of empathy and concern by my informants. So even though I would attempt to ensure "privacy" during interviews, the informants themselves often brought passers-by into our conversation, or others would decide to join us. Also, it was not possible for me, as a male researcher, to conduct an interview with a woman in any confined or private space. This was due to the existing *purdah* system and the extant norms of gender segregation which are connected with family honour and shame (see for example Rozario 1992). With this in mind,

when Salma began telling me about her son's illness with no visible unease, I decided not to interrupt her.

Salma told me that over the past three years, she had tried many therapies from both allopathic and non-allopathic practitioners for her son's illness. She had also tried to prevent him from catching a cold, or playing in the mud during the winter. It was heartbreaking for her to see him bedridden and struggling to breathe. As she spoke, she became emotional, 'Hay Allah, he suffers that much...you give his illness to me... you take his illness away. I cannot hold my tears when I look at him suffering to breathe.' Salma had a firm conviction that her son did not receive appropriate medication. She said:

We are from this area...this low land (*vati elaka*). We don't have ability to go somewhere else [to see good doctors]. Today if we had money we would take him to Dhaka or Mymensingh [to get better treatment]. Without money you cannot even step into the canoe [to cross the canal]. Everything is expensive these days. Even if we want to take him Mohangonj¹⁶, it would cost at least 500 taka. Disease for low-lying people means death. We people from the low lands die because of [not having] treatment. We cannot go to the city to get treatment. The medicines from the bazaar [the village practitioners whose dispensaries are in the bazaar] do not work. How can they? There are no doctors here who passed the exam. They cannot give medicine by inspecting the illness. They just see [the patients] and give medicines. Their medicines can suppress the illness only, cannot cure. If Allah wants, I can take my son to a big doctor in city, he will be cured inshallah.

This was one of a number of instances in my fieldwork that placed me at the intersection of the moral and the ethical. Where is that fine line between being an ethical researcher and a moral person? The way one conceptualises morality may differ from one person to another depending upon his or her ideology and philosophy towards life. Conversely, bureaucratic ethics review is an institutionalised set of rules governing the conduct of researchers; this set of rules must be adhered to if one is to be considered an

¹⁶ It was a common practice among my informants to make a hierarchical categorization between different locations based on the urbanization of the places.

ethical researcher. The terms of my ethics approval from my university clearly stated that I was to communicate clearly to informants that I was not a medical researcher, and that I was not to provide medical advice or medications during the course of my research.

While I was listening to my informants, Salma's son's or Fulbanu's story for example, I repeatedly found that I was unable to stop questioning myself about my role as a researcher, and responsibilities towards my informants. My earlier research in rural Bangladesh had taught me about the extreme poverty that shaped the rural villagers' lives. However, my fieldwork for this research project made me aware of a constant heartbreaking negotiation that villagers have to endure in cases of chronic illnesses.

Previously, I mentioned that I have had asthma for the past twelve years. After learning of the suffering of my informants, I came to feel differently about my own experience of illness. I felt ashamed. I felt I cared too much about my illness. In addition to seeing a doctor on a regular basis, I was able to maintain a self-management plan to deal with my asthma. My readings about the medical and non-medical aspects of chronic breathlessness had helped me to develop a plan. Having found that knowledge of the illness was helpful for me when managing my own breathlessness; I decided to share my experience and understanding of the illness with my informants. Needless to say, my biomedical knowledge of chronic breathlessness is not that of a trained biomedical physician. For example, I am not able to recognise different types of chronic breathlessness (such as distinguishing between asthma, emphysema, and COPD). Furthermore, I am not an institutionally-trained biomedical doctor with the "permission" to provide therapeutic suggestions.

With these shortcomings and restrictions in mind, what should I do when my informants expect me to tell them something about their illness? How should I situate my roles in a context in which I am always a recipient of information? Does their generous

contribution to my research not also impose a responsibility upon me to give something back to them in return? Therefore, although in the eyes of an institutionalised paradigm of illness I was not “authorised” to disseminate medical information, I decided to do so. I decided to share my own experiences of being breathless and the knowledge that I have acquired from reading on the topic. If I had not shared my own knowledge of breathlessness, they would have sought the assistance of untrained medical practitioners in the village bazaar. Locally, although these practitioners were the only available authorities of medical knowledge, many of them had wrongly interpreted the illness for my informants. Kulsum, for example, was told by her practitioner that her breathlessness would be gradually be cured if the injection was administered on time. The practitioner himself may not have been aware that existing biomedical knowledge does not advocate a cure for this illness.

I also decided to help my informants obtain Ventoline[®] inhalers (a brand name of Sulbutamol BP) a commonly used medication for treatment of breathlessness. Sometimes I bought inhalers for them and sometimes I gave them money and told them which Sulbutamol inhaler to purchase. In the case of Fulbanu, for example, I felt that it would be immoral of me to just walk away, leaving her struggling for breath. I gave her an inhaler and explained to her daughter-in-law how to use it. After using the inhaler, Fulbanu did feel a little better. At the same time, I knew that my inhaler would not cure her illness and that it would only provide temporary relief.

When my informants expected a permanent cure from “better” allopathic medicine from city doctors, their perceptions were based upon an awareness of geo-political division in healthcare. However, these perceptions were likely to be incorrect in biomedical sense. My responses to this perception varied from one context to another. Indeed, my opinion was probably self-contradictory. In some cases I told them about the chronic nature of the illness while in others I did not. In instances when I spoke of the continuous nature of the illness, I

told them about my own asthma and how I was making some changes in my life, e.g., staying away from dust and various allergens. I told them that numerous people around the world, despite suffering from this illness, were able to live satisfactory lives by dealing with their ailments on a regular basis.

On the other hand, I took a different approach when it came to individuals who were in particularly vulnerable and distressing situations, as was the case with Fulbanu. In such circumstances, informants were often bedridden due to their severe wheezing. I decided that I would not explicitly tell them that their wheezing was a chronic condition, and that even if they visited doctors in cities, their breathlessness may never be permanently cured. This was clearly not an unbiased decision of mine. However, I feel that it was the right thing to do. As I understood my informants, the prospect of a permanent cure for their breathlessness - at some point in their lives - was a very important source of hope. This hope, I believe, may have given them strength.

For these utterly distressed sufferers, it seemed immoral of me to tell them that their illness was incurable. Had I done so, I might have removed the last ray of hope they had of getting better. Furthermore, several anthropological studies have argued that while positive expectations may positively impact on the state of health, negative perception may also bring about negative results (Hahn 1997; Moerman 2000). Thus, in addition to providing some monetary help, I tried to boost their emotional strength by referring to some spiritual and moral metaphors. For example, I told them that there was nothing impossible in this world of God. I told them that human beings, with the blessings of God, were capable of making something happen which might otherwise appear impossible. Indeed, I believe that there are hundreds of things in the world that are still beyond our understanding. We are still yet to find an answer for too many of life's mysteries. We still see many things that we categorise as

miracles until we find an answer. In these ways, I tried to encourage these utterly distressed informants.

In the section that follows, I briefly present the experiences of a few individuals who travelled to cities to seek a cure for their breathlessness. I describe how their journey towards “the hope of cure” resulted in iatrogenic poverty in their lives and escalated their frustration.

Towards hope

Earlier, I briefly discussed the breathlessness of Ekram, an informant who worked as a *bepari* (hired labourer for harvesting activities) for most of his life (Chapter 4). In an attempt to improve his health, he experimented with several therapies from various sources. Like many others, his first point of consultation was with medical practitioners in the village bazaar. Initially, he also had received Butol[®]. He believed this medicine made him weaker even though it temporarily reduced his wheezing. Ekram’s practitioner from the bazaar also agreed on “the bone-eating nature” of this medicine. However, Ekram found this medicine to be the most affordable option for him.

On three occasions, Ekram made an effort to find “a cure” for his illness. Despite his poor economic circumstances, he decided to consult a “big doctor” in Mymensingh city. Initially, he thought he would sell his land to gather the money he needed to travel to Mymensingh. Later his cousin lent him money and, in return, he (his cousin) wanted to cultivate Ekram’s land. Ekram’s cousin also promised to give him a portion of the harvested crops. Ekram duly travelled to Mymensingh, a city with numerous medical centres. There, he consulted a private medical practitioner who suggested that he should undergo various blood tests, a chest x-ray, an ultrasound test, and a cough test. The cost of the medical examinations, food, and his hotel accommodation rendered him extremely vulnerable. Upsettingly, he said: “It is such a big city....does it have any head-toe (limit) in expense? Every minute [of stay] in

that city costs money.” After the third visit, the doctor told him that he would not need further consultation, which Ekram interpreted as having two possible outcomes. Either the illness would be completely cured after following the new therapeutic regimen, or it would never be cured. Optimistically, Ekram followed the prescribed treatment regimen for almost a year.

Despite the high price of the two prescribed inhalers, Ekram continued to take them. He was extremely disappointed to find his breathlessness recurred soon after he stopped using the inhalers. He ended up borrowing more and more money to be able to afford the medication. Throughout the course of his treatment, he also had to sell some of his land in order to be able to manage the cost. Meanwhile his cousin kept pressing him to either repay the debt or register the land under his (cousin’s) name. Other people who lent Ekram money also kept demanding that he pay them back. Thus, none of his plans turned out as he had hoped. He had strongly believed that the doctors from Mymensingh would cure his breathlessness, which would enable him to start work again and repay all his debts. He described his predicament as follows:

All lands are gone for my treatment. The last piece of land that I have I cannot sell it. If I sell it, what do I eat?

Thus, treatment from formal physician greatly enhanced Ekram’s poverty. After observing the intermittent return of his wheezing, Ekram became angry and stopped taking all of the medications prescribed by the Mymensingh physician. He could not see any point in continuing to buy the expensive medicines if they were “not effective enough to cure.” He stated that the better (curative) treatment for breathlessness needed ample amounts of money and that he would need to go to Dhaka to see the “best” doctors. He resumed drinking the Butol[®] syrup from the local practitioners.

I have not yet discussed the properties of Butol[®] syrup. According to the packaging, the syrup contains Sulbutamol, a common ingredient used in asthma medications. The company name is Cipla Bangladesh. I have taken asthma medications for more than a decade now, and I have always bought these medications from Bangladesh. Yet I have never heard of this company. When I spoke to a few of my doctor friends about this company, they laughed saying that they had never heard of Cipla Bangladesh either. Some of them were sceptical whether the syrup actually contained the ingredients on the label. Firstly, the syrup is extremely cheap: the price on the package says 23 taka (\$0.32), but I have seen the local practitioners selling it for as low as 15 taka (\$0.21). Other medications (such as Ventoline inhaler or Ventoline tablet) which also contain Sulbutamol are so expensive that my informants could not afford to buy them on a continuous basis. Second, I discovered that the informants did not experience the side effects (such as weakness or shaking of hands) when they took tablets or inhalers that also contained



Picture 13: The “bone-eroding” syrup

Sulbutamol. Thus, the Butol[®] syrup, which resolved my informants’ wheezing temporarily at the expense of undesirable physical side-effects, was a mysterious agent to both me and my informants. As Ekram spoke about his return to the syrup, I noted that he seemed extremely sad: his voice dropped. He seemed to be struggling with “the fact” that he was knowingly destroying his own body. Even though Butol[®] was now his regular medication, he still kept one inhaler prescribed by the Mymensingh physician. He tried to use this inhaler as little as

possible because it was very expensive and he did not want to finish it quickly. He would only resort to using the inhaler in the case of an emergency, such as when he could no longer bear his breathlessness.

Most of my informants considered themselves disadvantaged by their marginalised economic circumstances, as they were unable to travel to big cities to consult an urban physician. Neamul, for example, could not afford to see a physician in Mymensingh, so he went to Mohangonj, a nearby sub-district. Once in Mohangonj, although there was a government healthcare centre in the area, he visited a private clinic. He knew that a private doctor would pay more attention to his illness than a government doctor (see also Chapter 6). The consultation, however, left him feeling deceived after he discovered that the medications the doctor prescribed were those that would not permanently cure the illness. His frustration began when he saw that he was asked to use a *pump* (inhaler), the very type of medicine that he tried to avoid. The doctor prescribed him two inhalers and some tablets and asked him to return for another consultation in six months. Although the prescribed medications were basically unaffordable for him, he persisted with them for few months. He said,

The doctor from Mohangonj gave me this (showing the inhaler) along with some tablets. But the tablets don't work, only the inhaler [works]. I don't bring [i.e. buy] tablets anymore...they don't work. Who knows how long I will survive...my life depends on this [inhaler] now.

As his personal experience had taught him that the tablets were ineffective, Neamul did not bother to return for another consultation. When he found out that “the tablets were not working” he was very disappointed. According to Neamul, an inhaler, with its “oxygen” inside, will only cure the illness temporarily. For a permanent cure one needs medication such as tablets, which will “work from inside the body” and restore the ability to breathe. In this way, swallowing medication was seen as something that restored the body from the inside. By

contrast, an inhaler, the “air” ingredient, was not perceived as something that would dissolve inside the body but as something that would be exhaled.

Neamul was extremely frustrated that he could neither go to Dhaka nor to Mymensingh to see a “bigger doctor” to get “proper treatment.” He was in debt because of his medical consultation in Mohanganj and the high cost of the inhalers. In order to earn extra income, he started an illegal side business selling *ganja* (cannabis). He knew that his neighbours were saying bad things about him and his family because of his *ganja* business. He too felt that he had become “a bad person” for money, and was “making other people bad” by selling *ganja* to them. He heard several villagers pointing towards his family saying that all of his family members were involved in the business of *ganja*. But he always hid the drugs from the sight of his wife and son. This side business, however, allowed him to earn an extra 600 taka (\$8.50) every month, which helped him to purchase his inhaler. He insisted that he would not be able to afford the medication without those extra earnings.

There were two particular dimensions of the villagers’ hope for a cure that I wish to note here. First, their perception of potentially curative medicine was strongly associated with urbanisation, the hierarchy that was reflected in the uneven quality of available healthcare. The more a place was urbanised, the more it had improved healthcare facilities, technological advancement, quality education, and a better opportunity for a comfortable lifestyle. The informants mentioned six geographical locations during the interviews: Khaliajuri, Mohanganj, Modan, Netrakona *Sadar* (district town), Mymensingh, and Dhaka. I have placed them sequentially from the least urbanised to the most urbanised cities. Khaliajuri, the closest sub-district, had minimal urbanisation: it was the least desirable place for what my informants regarded as better treatment. My informants were convinced that the best doctors and medical institutions were to be found in urban centres such as Dhaka, the capital of Bangladesh. They

portrayed Dhaka as the hub of state-of-the-art healthcare. None of my informants, however, could afford to consult a doctor in Dhaka.

Second, it is important to note how their consultations with city doctors affected their lives. Upon discovering that their illness was not permanently cured, my informants felt deceived. Their frustration was intensified due to the unbearable cost that only added to their poverty. That increased poverty subsequently affected their social and familial relationships. However, these sufferers refused to accept that there was no hope of permanent cure for their condition.

The preceding stories illustrate that the use and misuse of medications among my informants are more complex than might initially appear. It is also evident that any simplification of their medication usage would be misleading.

Medication consumption

Concepts of compliance generally refer to the range of ways in which medications are used. One of the popular definitions of compliance describes it as “the extent to which the patient’s behaviour (in terms of taking medications, following diets, or executing other lifestyle changes) coincides with medical or health advice” (Haynes, 1979 in Trostle 2000). However, researchers have criticised this definition claiming that it treats sufferers as the passive recipients of advice provided by health providers (Rand 1993). Thus a new term, “adherence,” appeared. According to the WHO, adherence refers to “the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes, corresponds with *agreed* recommendations from a healthcare provider” (WHO 2003 emphasis added). This new definition stresses that individuals need to come to “an agreement” with practitioners about the prescribed treatment regimen.

In practice, however, there is little difference between the two concepts of compliance and adherence as both equally refer to therapeutic suggestions flowing from practitioners to individuals, and how well the latter is able to adhere to those suggestions. Notions of compliance/adherence have become so popular that, by 1999, more than sixteen thousand studies focusing on compliance/adherence had been included in the *Index Medicus* (Trostle 2000). The pervasiveness of these two concepts has influenced the ways in which authoritative public health institutions, such as the WHO, approach the management of chronic illness. In 2003, the WHO published a report titled “*Adherence to Long-term Therapies: Evidence for Action*” which examined “non-adherence” to therapeutic regimen by individuals with chronic illnesses (WHO 2003). Seeking to explain non-adherence among sufferers of asthma, the WHO proposed looking into the following five factors: socio-economic, health system, therapy related, condition related, and patient-related factors (WHO 2003).

The report argues that driven by various cultural and social factors, individuals may decide to underuse their prescribed medication, consciously altering the prescribed regimen depending upon whether the illness is symptomatic or asymptomatic (WHO 2003: 50-51). The report cites practitioners’ lack of knowledge and training in treatment management as a factor that contributes to non-adherence of their patients. It further suggests that practitioners need to be trained so that they can teach their patients the importance of medicine use and their vulnerability to the illness. The report proposed a range of behavioural strategies such as counselling, education, reminders, supervision, and memory aids to ensure adherence (p.55).

However there were a number of fundamental short-comings in this report’s sufferer-centred approach. The WHO report, in its fundamental framing of the problem in terms of compliance/adherence, emphasises the authority of biomedicine. The report focuses upon “factors” associated with sufferers while proposing a solution revolving around a pedagogical

notion whereby practitioners hold the ultimate power over the illness and wellbeing of the sufferers. Furthermore, the report does not address the uneven distribution of healthcare that may exist in many societies, especially in developing countries. Many Bangladeshi sufferers of chronic breathlessness, as we have observed, live in extreme poverty and far from sources of trained practitioners. They are therefore forced to obtain medicine from untrained local medical practitioners. This un-institutionalised practice of allopathic medicine is a common practice in several poor countries (Mull and Mull 1993; Pinto 2004; El Katsha, et al. 2006; Salim, et al. 2006; Cross and MacGregor 2009; Cross and MacGregor 2010).

James Trostle, one the first anthropologists to shed critical light upon the concepts of compliance/adherence, has explored the politics surrounding the use of these terms (Trostle, et al. 1983; Trostle 1988; 2000). Trostle claims that compliance and adherence are seriously handicapped concepts due to their inherent inability to analyse individuals' actual therapeutic behaviour. According to Trostle, these concepts encourage a certain line of scholarship rendering individuals vulnerable to the authority of the modern medical system. When individuals refuse to comply with the authoritativeness of biomedicine, they are labelled "noncompliant," which ensures further opportunity for practitioners to oversee the health of the individual and simultaneously avoid their own responsibility by placing the blame on the sufferers (Trostle 1988; Ferzacca 2000; Trostle 2000). Trostle proposes that the concepts of compliance/adherence should be understood as an ideology, that is, as "a system of shared beliefs that legitimize particular behavioral norms and values at the same time that they claim and appear to be based in empirical truths" (Trostle 1988):

Most compliance research defines and evaluates patient behavior in terms of imposed professional expectations. Most adherence research, even when it pays closer attention to a regimen mutually negotiated between health professional and patients, also defines fidelity to that regimen as the central component of proper care. Both compliance and adherence as research topics still generally ignore other health-related behaviors and practices (saving

medications at home, re-using prescriptions or sharing medications with others, using antibiotics in animal feed) that contradict the common perception of health professionals that they are central to all healthcare. (Trostle 2000: 41).

Taking together the problematic features of compliance/adherence, however, the issue of how an individual uses medication should not be considered an issue of lesser importance. Rather, knowing this issue in a proper way can contribute to better therapeutic outcomes. Anthropological investigations in India and the Philippines have shown that a cultural perceptions of habituation with a certain drug may influence whether or not a person decides to take that particular drug (Nichter 1980; Hardon 1992). Similarly, when discussing perceptions of hypertension among St Lucians in the West Indies, Dressler (1980) observed that the people of St Lucia variously understood hypertension through a form of sorcery (*obeah*), temperature changes in the environment, and food taking behaviour. In general, they preferred to use “bush tea” made from local plants to treat their symptoms rather than biomedical treatment. Many Latinos adhere to a perception of hot and cold in understanding illness, a humoral perception that influences their biomedical treatment regimens (Harwood 1971; Logan 1973). In this way, several scholars have explored individuals’ ethno-medical beliefs and cultural practices as factors relating to non-adherence to biomedical therapy, research which has contributed to a growing awareness that physicians should be sensitive to the cultural factors of individuals’ lives (see Blackwell 1973; Snow 1974; Weise 1974; Wiese 1976; Bastien 1992; Bastien 1995; Horne and Weinman 1999).

This notion of addressing the cultural beliefs of individuals, and of physicians adopting a sensitive approach to the cultural beliefs of individuals, may be connected to the concept of cultural competence in medical education. However, this idea of cultural competence training among practitioners has been criticised as a “backdoor to racism” as it threatens to give rise to a stereotyping of cultural beliefs (Lee and Farrell 2006). Of course, anthropologists do not deny the importance of culture in therapeutic processes. Rather, they

oppose the notion of cultural competence that reduces the culture into technical and static definitions (Kleinman and Benson 2006).

While exploring cultural beliefs of sufferers became a popular way of conceptualising medical compliance, another pool of researchers turned their attention towards the structural factors entailed in therapy use. For example, in his study of tuberculosis sufferers in Bolivia, Greene (2004) describes how neither culturally inappropriate communication between doctor and patient nor folk conceptions of tuberculosis were among the reasons why informants stopped taking their prescribed medication. In fact, perceived discrimination evinced by health professionals, expensive hidden costs arising from access to treatment, and poverty were the most crucial factors underpinning decisions to cease treatment. Greene argues that overemphasis on cultural difference when studying non-adherence may result in overlooking “the broader cultures of poverty and discrimination” (Greene 2004).

The stories of my informants present the extent to which medication consumption among rural Bangladeshi sufferers is complex. This is illustrated by the fact that they do not simply refer to cultural or structural factors that may influence their therapeutic experiences. Take the story of Neamul, for example. His *ganja* business, which was a way of affording inhalers, had nothing to do with his cultural beliefs. In fact, following Farmer (1996), it was a response to the structural violence of poverty. On the other hand, perceptions of inhalers as “the last treatment” and their reluctance to use inhalers as therapy could be interpreted in terms of local cultural beliefs which conceptualise the inhaler as something that carries air, as opposed to more painful (and thus more powerful) injections. In this way, my research demonstrates the importance of examining *both* the structural violence of poverty *as well as* the local cultural beliefs surrounding particular therapeutic regimes.

In turn, these factors are only two surface elements of a broader conceptual framework of hope. My informants demonstrated a persistent sense of hope that a cure for chronic breathlessness existed, a cure that quite possibly might be found with trained allopathic practitioners residing in cities. This form of hope could be seen as rooted in deception, given that existing biomedical conceptions of chronic breathlessness only focus on the management of the condition rather than on a permanent cure. Such perceptions of hope for cure are, however, generated from an existing heroic image of allopathic medicine, an image that constantly propounds an idea of cure as a battle fought and decisively won, rather than a routine management of illness (Kothari and Mehta 1988; Annas 1995; Manderson and Smith-Morris 2010b).

Sharon Kaufman (1988) observed the implications of such authoritative and powerful images of biomedicine on some Americans who had had a stroke. Her informants confronted a sense of loss which, Kaufman argues, were rooted in a particular cultural understanding of the body in American society that stressed individual autonomy, control and will. Therefore, even though much of the suffering that her informants experienced was beyond the scope of biomedicine, they nevertheless, with enormous hope, sought to restore their bodily autonomy from biomedicine.

Drawing on Kaufman's study, I find at least two distinctive elements in my informants' stories. First, the stories suggest that the assumption of allopathic medicine's ability to restore bodily autonomy might not always require the existence of an established, full-fledged, operational institutionalised biomedical system, like the one that Kaufman's informants experienced in American society. There was no formal physician within close proximity of my informants, and the practitioners whom they consulted were untrained. Additionally, most of the informants were non-literate, and lived in one of the most remote areas of the country. Yet they still believed that allopathic medicine (biomedicine) could cure their ailments.

Second, because they lived in a remote location, the spatial horizon appeared to them as an important factor that characterised their hope for a cure from allopathic medicine. In order to conceptualise the perceived inefficacy of the medicines obtained from local practitioners, they referred to the practitioners' lack of formal training on allopathic medicine. The informants were also aware of the fact that well-trained physicians were only available in the country's urban areas. Thus, they thought of highly urbanised settings (such as Dhaka) as places where medicine could work, if they could actually get there. This perception of a cure from distant places like Dhaka, which had a kind of "foreign" connotation to local Jalshiri people, may also be due to the fact that, for them, it was "difficult to obtain" allopathic medicine in those places (Whyte 1988: 225). In these ways, the expectation and hope for a cure persisted.

Furthermore, I noticed that, while many of my informants hoped for a cure from urban physicians, they did not constantly adhere to this hope. Their inability to travel to the city simultaneously affected the perception of hope, which became transformed into a state of ambivalence. In other words, ambivalence occurred because a form of hopelessness was already embedded in the ways in which their perceptions of hope were created in the first place. To continue consuming medication by spending more and more was an unrealistic expectation for most of my informants due to the fact that most of them earned only meagre income. Therefore, a constant oscillation between hope and hopelessness posed an existential dilemma in regards to whether they should or should not use particular medications. This dilemma, in fact, was not solely in the domain of illness and health. Due to poverty, their everyday encounters were often disappointing and frustrating, punctuated by occasional satisfaction. Therefore, in order to make our analysis comprehensive, we also need to be aware of the fluidities that characterise their hope of cure from allopathic medicine.

Finally, given the complexities involved in my informants' therapeutic experiences, focusing only upon cultural or structural factors would be an unsuccessful strategy. In fact,

these complexities also render the issue of compliance an unproductive discussion, and instead impel us to seek a greater understanding of the informants' lived experiences.

Chapter Six

Doctors of the Poor

Self-taught practitioners and their ethics of care

In treatment, I first must look at the patient, his economic circumstances, whether he would be able to continue medications. He has to survive first. I cannot just thinking of making profit for myself.

—Ali, a 55-year-old self-taught medical practitioner.

It was a leisurely afternoon at Sajal's dispensary when an elderly man came in and asked, "Hey, give me some tablets for [stomach] gas." Sajal gave him two rows of medication; the man left after paying fifty taka (\$0.71). The price of the medication, as it occurred to me, should have been less than fifty taka. Before leaving, the man signalled a hand gesture and Sajal took out a notebook and wrote down the amount he received. The man had not received any prescription for the medication, nor had he asked for one. After the man left, Sajal told me that the tablets were for "his family" (wife). The man had not mentioned anything about another sick person, nor had he provided an extensive list of symptoms before requesting the medication. Noticing my surprise, Sajal laughed and said, "I know the ailments of everyone in his family."

The experience of spending time with the rural medical practitioners like Sajal was a re-education for me. I learnt about the complex dimensions of relationships between the practitioners and their clients, and how these dimensions enabled my informants to avail medical help. The aim of this chapter is to examine the clinical practices of these local medical practitioners. The discussion illustrates the individualised nature of their services and the particular ethics of care that governed their interactions with clients. The chapter also

considers the broader politics that surround the social positions of these informal¹⁷ practitioners, and the non-recognition of their medical practices.

Rural practitioners and the poor

On that day, Sajal and I spent the whole afternoon together in his dispensary. He ordered tea from a roadside tea stall. He told me the story of how he gave up school and became a medical practitioner. Twenty-six year-old Sajal was one of the popular practitioners in the area. I had gone to meet him after some of my informants told me that Sajal's *daktari* skills (medical skill) were as good as his father's. His father, also a well-praised practitioner in the area, had stopped seeing patients and now mostly stayed at home after Sajal inherited his position at the dispensary. His father's positive image as a good practitioner had probably helped him to gain the trust of his own clients. The villagers respected Sajal and his father for being "good people," often spoke of their empathetic behaviour and the efficacy of their treatment. After only a few interactions we developed a friendly relationship. The way in which Bangladeshis observe social hierarchies may have helped in developing such quick rapport. Since one's age and gender are often the two most important determinants in developing friendships; individuals of a similar age and gender identity tend to develop sociable and friendly relations without any substantial hurdles. As gender is the overriding determinant in the society, especially in rural areas, it is uncommon for a boy to be friends with a girl, even if they are a similar age. The friendly relationship between us was probably possible because both of us were males and the age-gap between us was only a few years.

This sociable relationship was especially necessary to enquire into his professional background. The social status of medical practitioners like Sajal is lower than that of trained

¹⁷ I do not subscribe to the dichotomy of informal-formal as it eventually lands itself in the dichotomy of illegitimate-legitimate. However, in order to fulfil the purpose of my discussion in this chapter, I will, where needed, use the term "informal providers" to refer to self-taught practitioners. The use of the term in this chapter does not refer to any negative connotation.

physicians. Furthermore, Bangladeshi society often places high importance on formal education as a determinant of one's social status. Out of thirty practitioners from the village bazaar, only eight of them had studied up to twelfth grade or higher. In addition to the lack of formal education, these practitioners also did not attend formal medical training. Thus, they would likely to feel uncomfortable discussing their backgrounds with strangers. That is why, only after several meetings, I had asked Sajal about his professional background.

The lack of formal medical qualifications held by local practitioners did not, however, deter the villagers from calling them "doctors". Sajal, for example, was known as "Sajal *Daktor*" (Doctor Sajal). Among all the practitioners in the bazaar, five prescribed homeopathic medicine and the remainder practiced allopathic treatment. Because most of my informants preferred to consult allopathic practitioners for chronic breathlessness, I spent more time with them than I did with the homeopathic practitioners. There were no female practitioners in the bazaar. However, I did meet some female traditional healers (*kabiraj*) in the village. The female practitioners did not have separate consultation places outside of their homes, probably due to local cultural notions associated with gender divisions and social expectations that traditional healers practice at home. On the other hand, both allopathic and homeopathic male practitioners set up their dispensaries in rented rooms in the bazaar. Their places of consultation looked similar to pharmacies. Various medications were displayed on shelves that sat above a service counter. In these dispensaries, practitioners examined their clients, diagnosed illnesses, suggested therapeutic options, and sold medications. Often the practitioners worked alone at these dispensaries. Some of them hired young boys as helpers. The job of a helper was to do anything that the practitioner asked, including cleaning up the dispensary or fetching a specific box of medicine. In most cases, these helpers were young male relatives of the practitioners, although it was not uncommon for practitioners to hire non-relatives as well.

Sajal's story demonstrates how serving as a helper actually constitutes the first stage of training as a local medical practitioner. Sajal began working as a helper for his father twelve years ago, when he had just finished tenth grade at high school. Every day he would walk two hours to attend school which was located several miles from his village. During his student days, he often brought lunch for his father at the dispensary. He would sit in his father's chair while his father ate his lunch behind a medicine shelf. During this time, if any clients came to buy medicine or wanted to discuss an ailment, he would refer to his father (at the back of the medicine shelf) for suggestions. If the clients particularly wanted to consult his father, he would request that they come back later. In this way, he slowly started to learn about medications and how to advise people about their ailments. His father was happy that he was keen to learn about medications. But he became angry with Sajal when he (Sajal) failed to pass all of the subjects in his high-school "test exam." All tenth-grade students had to sit and pass this exam in order to take their first public examination, School Secondary Certificate (SSC). A pass would enable a student to commence eleventh grade at college. As Sajal had failed two subjects, there was no way he could sit the SSC examination that year. Disappointed, his father suggested Sajal leave school and start working at the dispensary.

Sajal was very happy with his father's decision because he enjoyed learning about new medications. Moreover, he did not particularly enjoy walking more than two hours to reach to the school each day. Initially, his tasks at the dispensary included unpacking big cartons of medications that had been delivered from the cities. He stacked the medications in their designated places, and brought medications to the front desk when his father needed them. Sometimes, while his father operated on a client's wound, he would stand nearby with cotton, thread, bandages, knife, and other relevant materials. His father asked him to memorise the relevant symptoms and medications he prescribed for various ailments. In this way, he received two years of hands-on training from his father. Later, his father decided to test

Sajal's skills by leaving him alone at the dispensary during lunchtime. For several months, his father went home to fetch lunch for Sajal, giving his son the opportunity to run the dispensary on his own. It was around this time, Sajal said, that his confidence in treating people developed. Soon, his father stopped coming to the dispensary each day, and only paid him visits from time to time. Thus, through a gradual process of learning, Sajal became a full-time medical practitioner without consciously realising what was taking place. Once he was practising on his own, the positive feedback from clients encouraged him to continue this work.

Whilst Sajal and I were sipping tea and discussing how he had become a medical practitioner, a middle-aged man came to the dispensary and said, "Doctor, give me some pain-killers [worth] ten taka." After hearing the details of his pain, Sajal gave him some tablets and explained the dosage. This interaction differed somewhat from my expectations of what a typical medical consultation would entail. In my mind, I pictured how the consultation would proceed: first with the patient describing his/her symptoms, followed by various questions about the illness from the physician, and finally, the patient leaving with a prescription in hand. These are expectations I have developed based on my experience of standard consultations with urban physicians in Bangladesh, in which the patient is also expected to pay twice: first, for consultation and second, for medications. By contrast, Sajal's client began the consultation by setting a limit on the amount he was "willing to spend." I was wrong to think that the man put the cost before the ailment due to his poverty. When Sajal gave him some painkillers and charged only five taka, the man said, "Not so cheap medicine doctor, give me good [expensive] medicine. I told you... I will pay ten taka, don't worry." This response reflected the particular ways in which villagers perceived meanings of medications, where cost is an indicator of value and efficacy. Anthropological discussions of social and metaphoric meanings of medicines are extensive (see, for example Van der Geest and Whyte

1988; Moerman and Jonas 2002). In this case, the man's refusal of the medication not only reflected that he was ready to pay within his capacity, it also showed that there was a non-static relationship between affordability and the willingness to get cured. In response, Sajal told the man that the prescribed medication was the right medicine for his ailment, even though it seemed cheaper. Sajal also told him that the expensive medications were not always the best medications. The client left, feeling confident that Sajal had not given him a cheap (ineffective) medicine just because he was poor.

After the client left, Sajal told me that he could easily have given the man another expensive medicine to "temporarily" satisfy him. He added that he knew that the pain would be relieved by the earlier medicine. He said that had he given the man another expensive medicine, he would never have consulted him again. The client would think him "a greedy practitioner" who was "always after the money" and had "no interest in curing one's illness." By recognising the client's negotiation between affordability and effectiveness, Sajal came up with a strategy that satisfied the client. His ability to convince the man with the inexpensive medicine was extraordinary. Sajal's strategies to satisfy the clients complemented the overall socio-economic marginalisation of the villagers. When the poor villagers came to Sajal or any other practitioner in the bazaar, they were not just passive recipients of the services. They were, in fact, active participants in the therapeutic process with the practitioners. Thus, the practitioners provided a service that was not only satisfactory, but also convincing to the villagers.

Initially, I thought that the practitioners employed intuition to calculate their clients' financial capacity to pay before suggesting a therapy. Further investigation revealed that a deep social relationship existed between these practitioners and their clients, which in turn, highly influenced their therapeutic interactions. In the instance of Sajal's interaction with the elderly man asking medications for gas problem –mentioned in the beginning of the chapter –

there was more than intuition involved in the therapeutic process. I noted how the man paid Sajal a sum that was higher than the value of the medications, and left without a prescription. Observing my surprise, Sajal laughed at me and said:

...I know the ailments of every one in his family. This family always comes to me for medicine.... We do not have prescription system here. The whole treatment depends upon the relationship between the doctor and the patient. For example, the owners of the shops surrounding my dispensary and their families always come to me for their ailments. In addition, the people who live close, on this right side of the bazaar, also come to me [for treatment]. Therefore, when a medicine is bought, I know who will take that medicine.

Most Bangladeshis who have sought medical treatment in urbanised cities would be surprised by Sajal's comments. I have been seeing the same physician in a private clinic in Dhaka for the past five years. He still needs to read my previous records before he is able to remember the details of my illness and the medications that he has prescribed in the past. This picture is typical of clinical interactions in Bangladeshi cities. Is it really possible for a practitioner to know and recognise all their clients, as well as their family members at a personal level? No matter how unlikely it might sound, this was the way all local practitioners in the village operated. It demonstrated the extent to which the social relations between rural practitioners and their clients differed from the relationships between urban physicians and their clients. In urban areas, an extensive use of modern technologies and hierarchies between medical practitioners and clients ensure that the social networks between the two groups seldom reach a personal level (see DiGiacomo 1987). By contrast, the relationship between these two groups in rural areas operates at an individual level where mutual understanding and diminished hierarchy greatly contribute to the nature of therapeutic interaction (see Van der Geest 1988; Whyte, et al. 2003). While the rural practitioners knew most of their clients at a personal level, this did not preclude them from also treating completely unknown clients, such as travelling traders in the village bazaar.

The villagers who consulted these practitioners for chronic breathlessness also received this personalised interaction positively. Another day during my observations at Sajal's dispensary, a middle-aged woman came with her four-year old son. Upon entering at the dispensary, she immediately began explaining the boy's ailments. She did not seek any permission to speak from Sajal. The existing gender hierarchy, where women usually adopt a submissive tone, was absent in the interaction. However, women tend to pay less attention to gender hierarchies in cases where the other person is a close relative, or someone they have known for a long time. In this case, Sajal had known the woman for a very long time, which helped her to comfortably describe her son's ailments without any hesitation. Her loud and authoritative tone in a space that exclusively belonged to the male practitioner did not just show a different dimension of local gender hierarchies, but also ensured her active participation in the therapeutic process that involved dealing with a man.

This mother was extremely worried about the "cold problem" of her son. The boy was neither eating nor sleeping because "the cold made him wheezy." Her comfort and informality with Sajal also came through in the way she frequently switched from one topic to another. She spoke of another bottle of medication that she had earlier taken from Sajal for her other son's fever. She had been delighted with the earlier medication, saying that it was very effective. She told Sajal that she still had a half-empty bottle at home, and asked if he would be willing to accept this bottle back in return for an adjustment in the price of the current medication he was about to give for this son. In a cordial tone, Sajal explained to her that he was unable to take an opened bottle back. She responded with a smile, probably realising that it was not possible for Sajal to re-sell that bottle to another client. She shrugged slightly, and then muttered herself, "If the medications were tablets; it would have been easy to return." Nevertheless, she reiterated the efficacy of the syrup and praised Sajal for "the good medication." While mentioning that she and her family members were regular clients of Sajal,

she expressed her sincere hope that he would examine her son appropriately and provide some effective medication. Rather than interrupting her at any time, Sajal played the role of an attentive listener. He remained actively engaged the entire time the woman spoke. He asked her about the wellbeing of her husband and her other son at home. While his attentive and engaged approach eased her anxiety, he took out the stethoscope from the drawer to examine the boy.

The dispensary was approximately eight feet wide and fifteen feet long. Sajal sat behind a low shelf-cum-desk that occupied more than half the width of the space, leaving a small passage between the desk and one side of the dispensary wall. The woman and her son stood in that passage. As I sat on a wooden bench behind Sajal's chair, I was closer to Sajal than I was to her. Sajal leaned towards the boy and checked his chest with his stethoscope for few minutes. Moments later, he blinked at me and said in a hushed tone, "Your case." I did not immediately catch what he said. I returned a questioning gesture. In an almost inaudible way, he muttered "*Hapani*," the local Bengali term for chronic breathlessness. As a local practitioner, Sajal was well aware of the local stigma associated with the illness and he did not want to upset the mother by pronouncing the term loudly. Instead, when the woman had described the boy's "cold" placing emphasise on not being able to eat or sleep due to "cold-related wheezing", he quickly recognised the woman's use of "cold" as an alternative idiom for the illness. Later, while talking to the woman about the boy's illness he always referred to his ailments as "a cold problem" or simply "this illness," evidently restraining himself from using any of the local terms for breathlessness.

After the examination, Sajal gave the boy two bottles of medication in syrup form and spent an unusually long time explaining the dosage until she was confident that she would be able to give the medication to her son correctly. The price for the medication was 198 taka. The woman paid 100 taka and said, "I just brought this (money); write down the rest [in a

requesting tone].” At first his expression indicated that he was not particularly happy with this, but then he smiled at the woman and took the 100 taka note. Throughout the consultation, Sajal never asked the woman for her name, her husband’s name or any other form of identifying information. At the conclusion of the consultation, he simply took out his notebook and wrote down the debt of 98 taka. This instance shows the extent of a rural practitioner’s personal familiarity with his clients, and their families. As Sajal noted down the woman’s debt, I caught a glimpse of a long list of various amounts in the notebook. I asked him whether he was confident that all of his clients would eventually pay. He gave me a confident smile and replied,

This is the system in the area [to pay in instalments]. A patient, for example, takes medicine worth 200 taka; he will pay 100 [taka] at the time of consultation and will pay the rest later. I write it down in my notebook. Next time when this patient comes for another illness, I ask about the money. Many times, I find that the patients are facing new problems and are unable to pay the amount at that time also. Most of my patients pay all their debts in Boishakh (the harvesting month in Bengali calendar). I know my patients. I have only a few patients who stopped visiting me after taking medicines on credit. However, most of my patients do not cheat on me. They probably think, “If I don’t pay the dues, he will not give me medicines again.” One client, for example, owes me 10,000 taka; he told me to provide medicines to all of his family members and he will pay me all of the dues in Boishakh. I trust him. He will give me all of the money, I know.

These tailored and flexible services made it possible for my informants to get medical help. However, as we saw in Chapter 5, many informants retained a firm perception that their breathlessness would be cured if only they could consult “a big doctor” in Dhaka. The next section presents a discussion on the poor people’s attempts to seek medical care in Dhaka.

Urban practitioners and the poor

“Money flies in Dhaka.”¹⁸ This was a phrase I heard over and over from many people in Jalshiri village. It refers to one of the country’s most urbanised cities and its glittering image as the centre of everything. Dhaka, a city extending over 815.8km², has more than 8.5 million inhabitants, most of which are internal migrants (Bangladesh Bureau of Statistics 2011). The phrase also reflects the perception among rural people that Dhaka was a place in which they could escape their extreme poverty. Often people perceive Dhaka as the city of hope, a place that supposedly offers a chance to survive for those who have lost everything, such as happens to many during floods, for example. Dhaka is also the city of optimism for all of those suffering from various illnesses, particularly those who have failed to find a cure in their local district towns. Dhaka symbolises a city of prosperity and a land of opportunity, especially to young adults of the country. I know many recent graduates who had studied in various cities and later moved to Dhaka in search of job. According to them, they “would not get a job without coming to Dhaka.” In fact, seven years ago, I was one of those graduates, who along with some friends from a far eastern district, moved to Dhaka soon after graduation. Somewhat ironically, neither all of those graduates nor all of my friends were able to secure satisfactory jobs, but these fresh graduates nevertheless kept their hopes alive, while trying to cope with the city’s busy lifestyles.

Dhaka is both literally and figuratively, the centre of Bangladesh. Not only is it geographically located in the centre, but as the capital of the country, Dhaka functions as the hub of all of the political and economic activities that determine the fate of the country. Although Chittagong, a port city, plays a critical role in the country’s import-export business, most of the companies have their head offices in Dhaka. It is from here that they operate the

¹⁸ *Dhakay taka urey*

core activities of their businesses, such as signing deals with international buyers. The centrality of Dhaka not only encompasses economics, business and politics; it extends to almost every sphere of people's lives, including healthcare.

Dhaka has many state-of-the-art hospitals and clinics, many of which provide excellent medical services. The government operates some of these services, while the rest are private. Some of the private hospitals are so ultra-modern that people sometimes refer to them as "five-star hospitals." The emergence of this type of five-star hospital with highly-skilled physicians and the latest advances in medical technology is a growing trend in developing countries (Cohen 2001; Majumder 2003). One such hospital in Dhaka is Square Hospital Ltd which is owned by the Square Group, one of the corporate giants in the country. I read a conspiracy theory about this hospital written by a prominent columnist in a newspaper (Mazumder 2012). The article claimed that the Square Group had initially built it as a luxury hotel for international tourists. The hotel was nearing completion when the 9/11 incident occurred in the US. The company quickly predicted that the future of Dhaka's tourism business would be in doubt, and immediately cancelled the plans for a hotel. Instead they opened the completed building as a hospital (Mazumder 2012). Opening a hospital in the heart of the city proved extremely profitable. In 2007, the Square Group spent 14 million taka on promotional activities alone to make it even more successful and today, the hospital has become an entrepreneurial icon in the country (Rashid 2009). International healthcare entrepreneurs also find Dhaka a lucrative place to invest. For example, Apollo, an Indian company operating a group of five-star hospitals, has opened up franchises in several big Indian cities and in foreign places like Dhaka and Mauritius. Cohen (2001: 16) has rightly commented that "Apollo is not only a hospital that looks like a five-star hotel, it is a five-star hotel that looks like a hospital." A study focusing upon three similar "five-star hospitals" – Square Hospitals Ltd, United Hospital Ltd, and Apollo Hospital Ltd – reveal their extremely

expensive services (Rashid 2009). Their services are so exorbitant that they are beyond the reach of many middle-class families, let alone the rural poor.

It is unlikely that it was just coincidence that almost all of these five-star hospitals are situated in Dhaka. My informants, even though many had never visited Dhaka in their lives, were perfectly aware of the presence of such expensive options of medical care that existed in the country. These people were so poor that even if they ever by some miraculous chance had the opportunity to consult a formal physician in Dhaka, they could never choose one from the five-star private hospitals. They would probably seek treatment in an overcrowded public hospital fighting its own resource crisis. These circumstances relating to my informants' capabilities and their perceptions of a cure in Dhaka inspired me to visit the public hospitals in the city. I was particularly interested in National Institute of Diseases of Chest and Hospital (NIDCH) because of its specialised wing for asthma. NIDCH, one of the oldest hospitals in the country, initially started as a tuberculosis hospital in 1955. After it became an institute, it started providing services for patients with all types of chest-related illnesses, not just tuberculosis.

In 1997, the government extended the services of NIDCH from a small-scale operation, to twelve district towns so that the inhabitants of those districts who suffered from chest-related illnesses could access better medical care (Alam 2011; NIDCH 2012). In 2005, the government established a separate wing, the National Asthma Centre, on the NIDCH's campus in Dhaka. Nowadays, this Centre in Dhaka and its facilities in twelve other districts constitute specialised public healthcare for individuals suffering from chronic breathlessness. Initially, I was not aware of any government chest hospital outside of Dhaka. Netrakona, the district where I conducted my fieldwork, was not among the twelve districts. The presence of specialised public healthcare services for breathlessness in only twelve out of sixty-four districts was probably another reason for my lack of awareness. I collected several newspaper

clippings on the frustrating services of these government facilities in those twelve district towns (Alam 2011). One newspaper report described that the services of those health centres were extremely inefficient and unsatisfactory. The services were so poor that most of the inhabitants of the twelve districts were not even aware of the presence of those government health centres in their towns. The lack of necessary equipment (such as nebuliser, and oxygen cylinder) often influenced the local staff to refer their clients to NIDCH in Dhaka (Alam 2011). In other words, poor people who sought modern medical care at a relatively cheaper price for their chronic breathlessness nevertheless had to travel to the National Asthma Centre in Dhaka.

In one late afternoon in the Asthma Centre, I met elderly Saidul. He was lying on the bed and coughing continuously. Saidul was a poor farmer and lived in a district adjacent to Dhaka. His daughter, Shaila, had brought him to the Centre after he experienced a severe attack of wheezing. After observing the serious nature of his condition, the physician who examined him recommended that he be admitted to the hospital. Saidul also appeared to suffer from severe malnutrition and weakness. As he lay on the bed, I could see his ribs protruding. In his small room of the Centre, there were sixteen other patients, each in their own beds. The room was full of mosquitoes and I could barely stand still in one place without being bitten. Shaila was trying to deflect the mosquitoes away from her father's chest and face with a piece of paper. It was late afternoon and the room was dark as there was no electricity. Shaila told me that it was the fourth shutdown of electricity on that particular day. The scant light filtering through the doors was insufficient to light the room. Slowly, as the sun set, the room became so dark that I could hardly see the corners of the room. When I came out into the corridor, I saw bright lights coming from the staff room at the end of the corridor. An electricity generator lit the room. I went towards the staff room. Just then, Shaila rushed into the staff room. She appeared extremely tense and nervous. She said that her father was

coughing violently. She wept, and begged the nurse to arrange “an oxygen” (nebuliser treatment) for her father. The nurse told her that without electricity, it was not possible to provide nebuliser treatment. Noting Shaila’s constant agitation, another nurse shouted at her: “You should understand less, we are here. We know what to do. Do you know more than the doctors?” Shaila quietly returned to her father.

Another day, I spoke to Bashir, a *tempu* (a motorised three-wheel vehicle that carries passengers) driver in his forties. Two days earlier, his wife had taken him to the Centre following a severe attack of wheezing. Bashir was utterly frustrated because he did not receive “free treatment and medications despite being admitted to a government hospital.” Instead, his admission to the Centre forced him to spend all of the small savings he had. His wife had to borrow money from a neighbour. Bashir was worried that he might end up with a large debt by the time he went home. He “blamed” his wife for this debt. On the day when his wife brought him to the hospital, he received nebuliser treatment on the spot and was prescribed some medication. He had requested that he be released immediately because he suspected that he would have to spend a large amount of money if he was admitted to the hospital. He also felt he was well enough to go home after taking the nebuliser. However, the examining physician wanted him to stay to “observe” his condition. After hearing the doctor’s suggestion, his wife started crying and begged Bashir to stay at the hospital. At this point in our discussion, a male nurse came to administer an injection for Bashir. After the injection, Bashir asked the nurse, “Brother, what is your name?” The nurse frowned, and then raised his eyebrows, a cultural signal expressing annoyance. It occurred to me that the nurse was probably too restless to respond to such “an unnecessary question.” In a somewhat harsh tone, he replied, “Why?” Bashir said that the administration of the injection was “so good” that he had felt only minimal pain and he simply wanted to thank him. The nurse, without waiting for

Bashir to finish the sentence, interrupted him with an extremely harsh voice saying, “You don’t need to know my name” and left the room straightaway.

As several patients and their relatives were dissatisfied with the hospital’s services, they used extremely abusive terms when talking about the physicians and the hospital staff behind their backs. Most of these abusive comments were expressed as part of patients’ frustrations with the huge costs associated with their treatment, “even though it was a government hospital.” As one woman said:

We would have gone to a private hospital if we had money. We come here because it is government [run]. They should give free treatment here, shouldn’t they? [They] not only ask us to pay for everything, they also treat us harshly.

It occurred to me, however, that such concerns over the expense of treatment often overrode their objections to the insulting, condescending, and uncaring behaviour from the hospital personnel. Apparently, rude behaviour by hospital staff was of lesser concern for these patients than were the costs incurred by purchasing medications, and other associated expenses. Bashir, for example, paid little attention to the nurse’s rude response when he asked for his name. He had probably already become accustomed to such uncaring behaviour the Centre staff. During our discussion, the only difficulty he mentioned was his rising debt, a problem he reiterated for me several times over. When I brought up the nurse’s behaviour directly, he commented that the hospital staff were, “too busy to speak to any individual patient.”

For the poor sufferers, the cost of treatment and the cost of living in Dhaka city were indeed extraordinarily high. For example, Anwar, a forty-five year old man who came from a southern district seeking treatment for his twenty-year old breathing difficulties, was frustrated by the cost of receiving treatment in Dhaka. Anwar worked as an automobile

mechanic in Madaripur and earned approximately 800 taka per day (\$11). He explained the costs associated with treatment for me:

Everyone rushes for money [here]. It seems that if they could, they would take money from me for walking on the street. See, brother, I am a very poor person; so much money they took from me! On the first day, they took 3000 taka just for various [medical] tests. Later I also bought medicine for 500 taka. When the test results come, then [they will ask for] more money; the doctors are burden-free after writing the names of the medicines. We are finished here in buying them. You won't believe how expensive the medicines for breathlessness are; see this inhaler? I spent 1200 taka for this. Even after spending so much money, the disease is not cured [permanently]... I am here [in Dhaka], my [automobile] garage is shut down now [in Madaripur], I have no income, but expense is high [now].

The ethnographic evidence presented above refers to a combination of three intertwining factors that has resulted in a denial of formal medical care to the poor: unavailability of treatment in the rural areas, poor care from the providers, high costs, and an institutionalised sense of exclusion. The physical unavailability of formally trained physicians in rural villages is the first stage of this denial. What is the rationale behind establishing most of the public and private medical centres in urban areas? Why are there so few public hospitals in rural areas? Why do most of the public hospitals in rural areas struggle with resource scarcity compared to their urban counterparts? During my fieldwork, I participated in a human-chain protest held in Shahbag, Dhaka. The demonstrators were demanding better public healthcare. A few human rights activists at the demonstration stated that public medical providers were unwilling to work in the rural areas because of the large monetary benefits they could gain by supplementing their government wages through engaging in private practice in the cities. Yet, when seeking medical care in urban areas, the poor were more likely to attend public hospitals because of the high expense involved in seeing a physician in private clinics. The activists also drew attention to the poor treatment of rural people by urban

physicians. My ethnographic evidence collected at the Asthma Centre corroborates these claims that the poor received harsh treatment from the staff in public hospitals.

Health workforce in Bangladesh

Where do the untrained medical practitioners like Sajal fit into our conceptualisation of health workforce? Scholars have categorised the health workforce into public and private (Mills, et al. 2002; Standing and Bloom 2002). The public sector includes all of the government-funded hospitals, primary healthcare campaigns or any other activities that directly or indirectly receive financial support from the government. By contrast, private practitioners are those who are not employed by the government health services. Yet, members of the community see them as providers of resources and assistance in cases of illness (Claquin 1981). In low and middle-income countries, this private health sector is so ubiquitous that they provide upwards of three-quarters of all medical care (WHO & USAID 2007).

This distinction between public and private, however, becomes blurred when physicians employed in the government hospitals also work in private clinics (Mills, et al. 2002; Patouillard, et al. 2007). As in many other developing countries, the private practice of public physicians is common in Bangladesh. These practitioners, who are registered physicians with M.B.B.S degrees or higher qualifications, usually conduct their private consultations in the evenings. Some rent private consultation rooms inside or near pharmacies; others are associated with private clinics and hospitals. These practitioners often hire assistants to manage patients whilst they are waiting. In Bangladesh, the income of a physician practicing privately is usually greater than that provided by the government. They often use their affiliation with the public hospitals to enhance their status and prestige, which in turn, helps them to expand their private practices so that many earn twice the remuneration provided by the government (see Gruen, et al. 2002).

According to Bangladesh Bureau of Statistics (2010), the number of registered physicians and registered nurses in the country amounts to 51,993 and 25,018 respectively. Of those, 38,537 physicians and 15,023 nurses are employed in the public sector, and the country still needs an additional 60,000 physicians and 280,000 nurses (Bangladesh Health Watch 2008). The shortage of trained public healthcare workers is especially concerning because most poor people cannot afford the high cost of services provided by private facilities. In addition to the cost of medications, there is also a substantial consultation fee to consult a private physician. In a country where seventy per cent of people live in rural areas, and more than forty per cent live below the minimum poverty threshold, many find it almost impossible to bear the expense of visiting a private clinic or hospital (Bhuiya, et al. 2012).

For the poor, consulting a public physician is their only financially viable healthcare option. It is therefore critical that more energy and effort is channelled into understanding extent to which the public sector meets the expectations of the poor. Studies show that 18,000 of 90,000 public healthcare personnel positions in the country are currently vacant, including 5,500 physicians' posts (Bhuiya, et al. 2012). Additionally, absenteeism is a problem among medical personnel working in the rural areas. Forty per cent of the physicians at the sub-district levels are regularly absent from work (IRIN News 2009 in Bhuiya, et al. 2012). The unequal distribution of healthcare personnel poses a big problem when there is a high concentration of physicians in the urban areas and limited numbers in the rural areas. Moreover, the workforce does not reflect the needs of the population, as the imbalance in the skills mix contributes to the inefficiency of the public sector (Bangladesh Health Watch 2008). Other inequities in the public health sector include lack of physical security for staff, informal fees, the presence of brokers, and neglect of the poor patients (Ibid.,). The overall poverty of the country is also reflected in the public health sector, which is too under-financed to meet the hopes of the poor. The sector suffers from a severe resource crisis (such as lack of

medicine and equipment), which takes a serious toll on poor patients who have to buy nearly everything themselves when using these facilities (Oxfam 2001; Zaman 2004). In other words, despite the fact that the public health sector is present at almost all administrative levels including *upazila* (sub-district) levels, the services they provide are inadequate, inefficient, and of a poor standard, especially those provided to the poor (Bangladesh Health Watch 2008; Cockcroft, et al., 2004 in Bhuiya, et al. 2012).

Nevertheless, if we only pay attention to the distinction between the public and private sector, we would not be able to understand the pluralistic medical practices of the country (Ahmed 1993). Claquin (1981) has presented seven categories of Bangladeshi practitioners. They are allopathic practitioners with M.B.B.S. degree; practitioners without medical degrees or licenses who dispense allopathic drugs, including antibiotics; practitioners using homeopathic medicine who are either institutionally trained or self-taught; ayurvedic or unanic practitioners who are either institutionally trained or self-taught; traditional midwives (*dais*) who learn their crafts through apprenticeship or personal experience; spiritual healers who do not use medicine but heal using ritual chanting, amulets and charms, and others (such as bone setters) who do not fall into any of the other six categories (Claquin 1981: 153-154). The medical practitioners who provided treatment to the Jalshiri villagers are best classified as practitioners with no medical degree. The presence of practitioners trained in numerous different ways evidently makes our earlier categorisation of public and private too simplistic. Thus, some researchers have used the categories of “formal” and “informal” to cover the wide ranges of medical practices (Ahmed 1993; Bhuiya, et al. 2012). The “formal” practitioners are those who are qualified medical professionals or paraprofessionals such as physicians, nurses or paramedics who work in public or private sectors (Bhuiya, et al. 2012). By contrast, the category of “informal” practitioners refers to the “variety of healthcare providers who are

unlicensed, unregulated private providers with limited to no formal or institutionalised training or required medical qualification to provide healthcare services” (Ibid., : 3).

Formal practitioners

In Chapter 5, I discussed three informants from Jalshiri village who sought medical care in Netrakona and Mymensingh cities. Of these three informants, only one went to a public hospital. The other two went to low-cost private clinics, even though they knew that seeking treatment from a public hospital was cheaper. They held a strong suspicion that public physicians would not take their ailments seriously as they would not receive large consultation fees from seeing them. They believed that a physician would pay greater attention to their illnesses if they went to their private clinic. Ironically, all three informants found their interactions with their urban physicians disappointing. According to them, the physicians were “greedy,” “unconcerned,” “mostly interested in getting their fees,” and “always forcing them to spend money on various medical tests so they could receive financial benefits from diagnostic centres.” Their experiences generated deep feelings of anger and mistrust of “the business intention” of urban physicians among my informants. One elderly man in his eighties angrily said,

All of these [urban] doctors are sons of a pig (*shuorer baccha*, an extremely vulgar insult in Bangladesh); they know everything about the disease, but they won’t tell you. They won’t tell you the real reason of how you get the illness. Why would they? If they tell, their business is finished. The people will start avoiding those things and would become free from disease....no one would go to them anymore.

Although it is tempting to regard this mistrust as a “misconception” of urban physicians, this perception is likely to have stemmed from the high costs involved in seeking treatment from urban physicians, and the consequent frustration associated with the treatment outcome. Those rural people willing to get treatment from urban physicians have to start spending money even before the actual medical consultation. Once they reach the city, it is

common for them to meet brokers (*dalal*) at the bus stops or train stations who will take them to a health centre. The Bengali term “*dalal*” is a socially condemned word. Society disapproves of the work of an intermediary who earns financial benefits just by filling in communication gaps. Nevertheless, these intermediaries exist in many spheres of people’s lives, from land registration to public and private healthcare sectors. The broker usually brings the poor villager to a mediocre or lower standard clinic in return for a kickback from the management. At the clinic, a physician might suggest several medical tests. As such, the people in Jalshiri held a strong perception that urban physicians would make many “unnecessary” suggestions, such as recommending nonessential medical tests in order to receive illegal kickbacks from diagnostic centres. Some even told me how they had been asked to re-take certain tests if they had ignored the physician’s recommendations and gone to a different diagnostic centre.

The suspicions of my informants regarding physicians, and whether they were receiving commission from diagnostic centres may have reflected a cruel truth in the country’s formal health sector. Last year, while I was in Bangladesh, I accompanied my father to a well-known private hospital in Dhaka. My father suffers from hypertension and a sleeping disorder, and receives regular treatment for these conditions from a doctor at this hospital. The doctor, a prominent physician, has received his medical training both at home and abroad. My father believes that this physician gives him extra attention due to their shared religious identity, as they are both Hindu, one of the minority religious groups in the country. My father, who usually resides in a rural village, has been travelling to Dhaka twice a year for the past five years to consult this physician. Although a trip to Dhaka takes more than a day, he tries not to miss any visits. At the end of each visit, the doctor gives my father a list of medical tests he should undertake before his next appointment. Each time, my father takes this list to the pathology department at the hospital and then collects the results the following

evening. Once he has the results, he then waits to see his doctor, sometimes spending 5 to 6 hours in the waiting room.

The day I accompanied my father, he noticed that there were no substantial changes in the test results over the past few times, and that the physician had made no substantial changes to his regular medication during this time. He asked the physician, “Sir, you are Hindu, I am Hindu too.... Why do you ask me to undergo all of these tests each time I come to see you?” As a Bangladeshi, I felt this to be a bold question for a patient to pose to his physician. Cultural norms demand that patients maintain a submissive position when speaking to their physicians. Therefore, I was quite surprised when my father asked him the question directly, although my father smiled to soften the challenge implicit in his question. His relationship with the physician for over five long years, and his perceptions of religious similarity may have enabled him to pose that otherwise “uncomfortable” question to his doctor. The physician responded with a hearty laugh. He pointed to the lavish hospital infrastructure and, jokingly, he said that if patients did not undergo these medical tests, the hospital would be unable to run efficiently and effectively, and he would not receive his salary either. His joking tone softened what was in fact the harsh reality of the high costs of good medical care in Bangladesh.

The harsh reality of Bangladeshi healthcare is that, as far as the poor are concerned, high quality treatment is mostly unaffordable. When poor people spend considerable sums on travelling to the city, paying physicians’ consultation fees, and then handing over more money for numerous medical tests and costly medications, it is understandable that they expect their illness will be cured permanently. However, these expenses, rather than leading to a cure, cause them to fall into “iatrogenic poverty” (see Khun and Manderson 2007), and they are left feeling duped by the formal healthcare system. An elderly man named Manik illustrated these frustrations for me, saying:

My doctor gave me many types of inhalers: one cost 1300 taka, another 800 taka. I took them for many days. But, see, no improvement. I still have this disease... For this inhaler [showing his Ventoline inhaler] I spent 300 taka although it says 180 taka on the pack. I can only go for twenty days with this. Listen son, Allah takes revenge on this kind of practitioner. Doctor Nazim was very famous. It was very expensive to see him. He took money from the poor patients and built a hospital on his name. However, the hospital is so expensive that the poor cannot go there. Once, the Doctor himself got sick. It was such a big disease that there was no medicine [to cure]. He even flew abroad for treatment, but he died. Listen, Allah has an arrangement for everyone.

Like Manik, most of my informants shared a sense of exclusion from the formal medical system. They realised that the marginalised socio-economic conditions prevented them from attending state-of-the-art private hospitals. They knew that they would receive insufficient attention from urban physicians. They believed that seeking treatment in the cities would drain their limited resources. So, when Rabeya, whose story I described in Chapter 5, said, “The people who are rich, take a look at them.... they are getting hi-fi treatment,” she was not only referring to the advanced urban medical treatment that rich people enjoy, but also expressing her sense of exclusion from all of those facilities. In other words, the poor in Bangladesh experience a denial of medical care from the formal health sector.

Informal practitioners

Due to the inadequacies of the formal health sector, the local (informal) self-taught medical practitioners have become an affordable and accessible source of medical care to the poor rural villagers (Bhuiya 2009; Wahed, et al. 2012). At least three particular characteristics of their services make their roles highly beneficial for poor villagers. The first aspect was the use of trust as a form of currency. This form of currency may be invisible, but it is very powerful. Although the rural poor often did not have cash in hand to pay for their medications, the practitioners did not refuse them medical help. The practitioners allowed them to get medications solely based upon mutual trust, knowing that they would clear their debts in a

timely manner. Related to this mutual trust was a tailored payment system that the practitioners offered to their clients. This method, however, was not the haphazard system it might appear on surface. It occurred in quite a systematic manner. Sajal, for example, updated his records in his notebook whenever the clients paid an amount. As most people's livelihood depended upon crops, the payment system accommodated the harvesting period and adjustments were made when necessary. The greater concern for practitioners then, was the possibility that a natural disaster might occur during the harvesting season, rather than the matter of whether their clients could be trusted to pay their debts.

This much needed trust was especially important to my informants who might just have to show up with little or no money for treatment. Given that Bangladesh does not have any health insurance system, it is highly unlikely that an urban physician in Bangladesh would allow an entire year for his or her clients to pay their consultation fees. It would be unthinkable for me to ask my own GP in Dhaka to allow me even one week to pay his consultation fees. I always have had to pay his consultation fees in cash and upfront. If I did not have enough money to pay these fees, I would just schedule my doctor's visit on another day when I did have the money. This situation also holds true for many developed countries as well. Michael Moore, in his investigative documentary, *Sicko*, shows how many US citizens are unable see a physician, as they cannot afford to pay health insurance premiums. In the film, it is absolutely heartbreaking to see how some of these people have to operate on their wounds themselves at home, as they cannot afford the cost of surgery at a hospital (Moore 2007). In other words, in a formalised urban healthcare system, trust has a low currency value; one is either in or out of the system.



Picture 14: A self-taught practitioner in his dispensary

Second, the level of trust between the informal practitioners and their clients often takes the form of loyalty, and this applies to both parties. A practitioner might expect that his regular clients would always consult him whenever they or their family members needed medications. They might react strongly if they discovered that their clients had consulted other practitioners, without a convincing reason such as the dispensary was closed. The clients, in turn, might expect a bargain deal on the price of medications. They might also expect a “right to a return” policy that would allow them to bring back unused medications, which the practitioners would then accept and adjust the price of other medications or debts accordingly. If, however, the client had purchased the medications from another practitioner and went to return them to their regular practitioner, the latter would usually either refuse to accept them or undervalue the prices before accepting. Out of loyalty, clients would also expect some sort of pledge (as opposed to just an expectation) from their regular practitioners that they will take more time to inspect the illness, listen carefully to details of the ailments, and most

importantly, provide better (effective, curative) medications. Therefore, in the case where the woman was reminding Sajal that her family members were his regular clients, she was referring to the promise implicit in the relationship, i.e., Sajal must examine her son thoroughly.

Third, the practitioners operated according to an ethics of care that was at odds with the urban practitioners' treatment. Sajal, for example, did not just dispense an expensive painkiller even though his client deemed the earlier tablet "cheap" (ineffective). Similarly, Ali (the practitioner whose quote begins the chapter) told me that he always tried to determine the socio-economic status of his patients before prescribing medications. In addition, the practitioners care for their clients extended beyond therapeutic matters. This was illustrated in Chapter 3, when a groom-to-be came to a practitioner to investigate whether the girl he wanted to marry was suffering from chronic breathlessness, and the practitioner avoided causing harm to his client (the bride-to-be) by not telling about her breathlessness. The practitioner knew that if he disclosed the girl's illness, the prospective wedding might not take place, which would be particularly distressing for the girl's family and her life would be "destroyed." Due to various issues such as dowry, arranging marriage of a girl in rural Bangladesh is an issue of great difficulty. That is why the practitioner metaphorically referred the matter as a "life-death" situation for the girl. In other words, unlike urban physicians, these practitioners' relationships with their clients are neither just limited to therapeutic care, nor do they end after the client has received medication. Rather, their roles are complex and deeply mediatory in the villagers' social lives.

Informal practitioners and the poor

The reasons that the poor in Jalshiri find the informal practitioners' services comfortable go beyond any of these tangential benefits involved in their relationships. In this context, the relationship between practitioner and client clearly involves a mutual discussion.

How do we explain this mutuality? One explanation may be that the existing non-recognition of practitioners may have influenced them in such a way that they maintain a passive role in their interactions with clients. This explanation, however, fails to address the idiosyncrasies and diverse aspects that distinguish their relationships.

In my opinion, the mutuality in their relationships, should instead be observed in terms of their societal predispositions, or their habitus (Bourdieu 1977). Bourdieu used the concept of habitus to develop a theory of action, in which he described the logic of why individuals behave in a certain way in certain social contexts. Through the concept of habitus, which refers to societal dispositions of individuals, he explains how these dispositions are reflected through individuals' activities. For Bourdieu, society is not something that is constituted externally. Rather, it is the way the body positions itself in the social world, and how the social world also inhabits the body. Although Bourdieu refers to social dispositions, he rejects the notion that social structures solely determine individuals' actions. In fact, he rejects all deterministic and mechanical explanations of individuals' actions, arguing that individuals are not just passive actors (Bourdieu 1977). Rather, these dispositions "guide them [individuals] in their creative responses to the constraints and solicitations of their extant milieu" (Wacquant 2006: 316). Thus, for Bourdieu, there is always a constant dialectic relationship between one's agency and the social structure.

Clearly, there are similarities in the social conditioning of the rural informal practitioners and their clients. Both evinced deep insight into the overall marginalised socio-economic conditions of the inhabitants of the area. Both had experienced how an overnight flash flood can inundate vast amounts of crops, irrevocably altering the lives of villagers. The ways in which this pre-familiarity and relationship to circumstances are predisposed in the practitioners and their clients, and later motivating their actions, can be described as "the internalization of externality and the externalization of internality" (Bourdieu 1977: 72). In

spite of the similarities in their societal dispositions, the interactions between practitioners and their clients are not straightforward. Take, for example, the negotiations between Sajal and his clients in terms of the affordability, flexibility of payments, and the perceived efficacy of the prescribed medication. Sajal's clients made decisions and took action regarding the state of their illness based upon thoughtful negotiations of their marginalised socio-economic condition and their subjective understanding of the prescribed treatment's efficacy. Both parties actively engaged in the process of the therapeutic consultation. Due to shared societal predispositions, and pre-familiarity between the both parties (Bourdieu 1977; Ram 2010), this active negotiation occurred without any visible discomfort.

By contrast, those who sought treatment from urban physicians described it as a journey to "a different world." Elderly Fuli, for example, whose story I described in Chapter 4, broke her ankle and refused to go to a public hospital in a district town when her husband wanted to take her. Explaining her refusal she said, "I don't like to go there [Mymensingh city], I get scared of all these buses and trains. I feel I might get lost. How would I get home if I get lost? This is very scary." Her trepidation was based on a previous visit to an urban physician, and the discomforts she experienced seeking medical care in the city. On that occasion, she had been forced to wait in a separate room for a long time until an assistant called her name. It is possible that during this wait, the setting of the urban physician's premises may also have intimidated her and the highly formal ambience of her surroundings may have prevented her from expressing the ailments to the physician in a comfortable way. In fact, one cannot just expect to be able to walk into an urban physician's clinic and seek consultation with the physician straightaway. Clinics usually have particular formal procedures that dictate the interaction between staff and patients. Such procedures are at odds with the expectations of many rural people whose social worlds are characterised by greater informality and a sense of reciprocity.

In 2011, I visited a private clinic in Dhaka as part of my fieldwork. The clinic had three assistants through whom patients had to pass before they could consult with the physician. The first assistant sat in the waiting room with a long list of the patients. His main duties were to control the chaos of the waiting room and to send those who were waiting on to a second assistant, who was located adjacent to the physician's room. The second assistant checked their blood pressure, weight, and asked some routine questions such as how long they had been suffering from their breathing problem. Finally, the third assistant, standing at the doorstep of the physician's room, would grant permission for the patient to enter into the physician's domain. This third assistant operated in response to a bell, rung by the physician at the end of each consultation. At the sound of the bell, the third assistant would usher in another patient, and take the consultation fees from the previous patient as they departed. The whole process reminded me of a mechanised factory conveyor belt operation, where the patients are stopped at each stage to receive a particular service before receiving the final "touch" by the physician. It is easy to see how these procedures could be dehumanising, particularly for rural villagers, who are accustomed to see their local practitioner in an informal manner and without any major delay. Given this contrast, it is unsurprising that they may feel discouraged and intimidated by such a mechanistic atmosphere.

The physician's extraordinarily authoritative tone, which appeared as a "final verdict" with very little room for any appeal from the patient, was also entirely different to the way local self-taught practitioners interacted with their clients. In addition, the stringent time constraints of busy physicians in urban areas may also exacerbate the rural people's discomfort. The clinic I refer to here was probably one of the busiest private clinics for treatment of chronic breathlessness in Dhaka city. The physician who owned the clinic was a prominent physician of chronic respiratory diseases, renowned for his expertise. Because he regularly wrote in popular newspapers about chronic disease, he was one of the best known

names in the field. In our conversations together, he described himself as “the pioneer” of asthma treatment in Bangladesh. On one particular evening, when I was about to leave his clinic at 11p.m., I told him I was surprised that he saw patients until so late. In response, he proudly boasted that he had seen 120 patients that particular evening. I knew that he arrived at the clinic a little before 6p.m., which meant that each patient received no more than two and half minutes of his precious time. Indeed, I thought, time is money!

Despite the critical role performed by informal practitioners, their contributions are not only unrecognised in the formal healthcare structure, but their practices are also seen as illegitimate. This next section discusses the politics of unrecognition, and how illegitimacy feeds the interests of trained physicians themselves and the expansionary goals of pharmaceutical corporations.

Politics of unrecognition and illegitimacy

When I briefly mentioned my research project to my physician in Dhaka, he was curious to know. At some point, I told him about the self-taught medical practitioners who provided a valuable service to those who had little or no access to trained physicians. My physician gave me a strange look. Initially, he did not quite understand which practitioners I was talking about. But once he understood, he burst into a loud laugh and exclaimed, “Oh! *Hatuir daktars!*” An English translation of his comment would be “Oh! Quacks!” For the purposes of my analysis, however, I begin with a literal Bengali translation of his comment to discern the deeper ethnographic meaning of his comment. Literally, the Bengali word *haturi* means “a hammer.” In Bangladesh, a hammer is a tool associated with the carpentry profession. Carpentry is a predominantly male profession that is associated with a lower socioeconomic status in Bangladeshi society. Metaphorically speaking, a carpenter has tools such as hammers, and saw-blades, while a physician also has his/her own tools, such as

stethoscopes, and blood-pressure monitors. My physician's comment "*Hatuiira daktars*" is a widely used slur in Bangladeshi society. People, especially urbanites, use this term in a joking idiom to refer to untrained rural practitioners, suggesting that they treat their clients with "a hammer" because they lack the necessary tools of a trained physician. The term "*Hatuiira daktars*", however, does not just refer to a lack of diagnostic instruments; it also infers a lack of institutionalised medical knowledge. Thus, my physician's use of the term had marked derogatory connotations, emphasised by his derisive laugh, which reflected his strong disapproval of the work of the untrained practitioners.

My physician reminded me of other physician friends of mine, who saw themselves as the sole legitimate practitioners of medicine. Their frequent comments indicated that they deemed other non-allopathic practitioners to be less legitimate. Similarly, urban literate inhabitants also showed their disapproval of untrained medical practitioners (see Chapter 5). In marked contrast to their views of formal trained practitioners, who were seen as "genuine," they referred to untrained medical practitioners as "illegitimate" and "frauds." In other words, the dichotomy of informal-formal is replicated in practice as illegitimate-legitimate. My physician's disapproval of informal practitioners not only signalled the degree to which he condemned their activities. It was also a strong reflection of how he saw his own practice. As a trained biomedical physician, he knew that he enjoyed a more superior social status in the society than what any rural practitioner could aspire to. This realisation became evident in the negative labelling followed by his guffaw. Similarly, his derogatory references to rural self-taught practitioners only served to reify the trained practitioners' apparent view of themselves as the sole possessors of the superiority, authority, and legitimacy required to oversee individuals' health and illness.

Thus, the physicians' perceived superior status also refers to the existing tensions between multiple medical practices in the society. There is an exhaustive anthropological

literature on medical pluralism (Djurfeldt and Lindberg 1975; Leslie 1976; Janzen 1978; Kleinman 1978; Frankenberg 1980; Press 1980; Valentine 1984; Baer 1989; Leslie and Young 1992; Nichter and Nichter 1996; Nichter 2001; Broom, et al. 2009). The literature focusing on the Indian subcontinent investigates the ways that religion, class, caste, gender, colonisation, and everyday cultural practices have continued to influence therapeutic practices in the region (Bala 1991; Arnold 1993; Khare 1996; Pati and Harrison 2001). The support that biomedical practitioners have received from the state since the colonial era has contributed to its current hegemony in the sub-continent (Sujatha and Abraham 2009). Despite the higher social status of formal biomedicine and its relationship with the discourse of modernity, these modern medical practitioners have failed to provide their institutionalised medical services to most Bangladeshis, especially those living in marginalised socio-economic circumstances. These disadvantaged populations often find non-biomedical practitioners or informal practitioners of allopathy / biomedicine to be the only accessible source of medical care for their ailments (see also Pinto 2004).

Big pharmaceutical companies cleverly exploit this unrecognition of rural practitioners to expand their sales in remote areas. Medical representatives of pharmaceutical companies periodically visited Jalshiri village to hold “training sessions” with local practitioners. While the ostensible purpose of these sessions was to increase practitioners’ medical knowledge, it soon became clear that their fundamental aim was to increase the sales of the companies’ pharmaceutical goods by motivating the practitioners to prescribe them. Sajal arranged for me to attend one of these trainings, which was organised by Popular Pharmaceuticals Ltd (PPL), a well-known Bangladeshi company owned by Popular Group, a corporate giant. In urban Bangladesh (as elsewhere), it is common practice for medical representatives from pharmaceutical companies to regularly meet physicians to persuade them to prescribe their respective company’s medications. However, the one-on-one consultations that took place in

the urban areas were absent in rural areas. Rather, medical representatives would travel from cities to meet with rural practitioners in a pre-arranged group training session which they called a “conference.” Coincidentally, the training session that I attended was the first one held by the PPL in that area.

The local practitioners were not prescribing PPL’s medications, presumably because other companies besides PPL regularly visited them to promote their own medications. Alam, PPL’s newly-appointed local sales representative, convinced his district manager of the importance of arranging a training session in this area. The district manager arranged for his superior, the area manager, to speak at the session. Alam was responsible for contacting all the local Jalshiri practitioners. Before joining PPL for a better remuneration package, Alam had earlier worked for another pharmaceutical company. He had already arranged many such training sessions and had developed a good rapport with many of the practitioners.

On the day of the training session, I along with a few practitioners, waited for two hours for the speaker to arrive. The venue, a tin-shaded half-broken clubhouse in the village bazaar, had several empty chairs. Alam was embarrassed because the speaker was late. He came to assure us that the speaker was on his way, and that he was delayed by the poor transportation system. Soon, Alam received a call on his mobile. He told us that the “conference” would start shortly as the speaker’s boat had just arrived at the jetty. Alam then rushed off to inform the other practitioners who were yet to arrive. Within a few minutes, approximately forty practitioners, including some from adjacent villages, filled the room. In addition to some old plastic chairs, Alam had also brought a few school benches from a nearby primary school to arrange seating for everyone. The speaker, an educated urban man, had brought a laptop with him. The use of a laptop is associated with prestige, and a higher socio-economic status in the village. I saw some practitioners periodically staring at the laptop and talking about it to each other. Apart from the laptop, the whole room resembled a typical

rural Bangladeshi school with a teacher (the speaker) sitting behind his desk. A senior local practitioner from the bazaar sat next to the speaker on one side, and on the other side sat Alam.

Mahbub, the speaker, was in his forties and worked in a senior position for PPL. He managed the company's sales in three districts, including Netrakona. I had earlier observed that medical representatives in cities always wore suits when they were on-duty. This speaker, however, stood out to me because of his informal clothing, despite being technically on-duty. Nevertheless, his smart tucked-in shirt, urban dialect, and laptop set him apart from the conference participants. He started by apologising for arriving late, exclaiming how surprised he was to see the poor standard of infrastructure in the area. He had come from Mymensingh, a district adjacent to Netrakona, and had found that he had to undertake seven changes in transport, including an hour-long journey in a small canoe. He said that while he could easily have sent another staff member who worked under his supervision, he opted not to because he "always wanted to see this beautiful lowland region (*vati elaka*)" and "wanted to meet the wonderful people of the area (pointing to the practitioners)." The conference brought this chance "to fulfil his long-held wish." While listening to him wax lyrical about his fantasies of visiting the area, I wondered whether he was genuinely interested in what this area had to offer, or whether his comments were just another corporate sales technique designed to develop rapport with the potential profit generators for his company. Nevertheless, it occurred to me that his comments had the effect of breaking the ice with his audience of rural practitioners, and creating an easy informal atmosphere in the room. He went on,

You all are providing medical services to the people of this area for long time. I am not here to teach you. You know all of these things [which I have to say]. I have just come to refresh these known things to you. All of you are very experienced physicians and working in this profession for many years, I cannot teach you anything.

After this speech, he kicked off the discussion by talking about some popular television commercials of PPL, which reinforced the renowned reputation of the company. He

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also referred to another well-known company in Bangladesh famous for producing Orsalaine®, a popular oral rehydration therapy (ORT) brand used to treat diarrhoea. The practitioners all knew of this company who distributed the widely used ORT drug. Mahbub surprised the practitioners by mentioning that this company – famous as it was for producing Orsalaine® - actually manufactured some of their pharmaceutical products in PPL's manufacturing plants due to the "high standard" of PPL equipment. Later, Mahbub said that his company was the first Bangladeshi company to produce many lifesaving medications used in ICUs and operating theatres. As he spoke, he continually stressed "the pioneering works" and "high standard" of PPL, as well as the strength of the company's reputation both at home and abroad. By using such powerful adjectives he thus set up an impressive context in which to present the pharmaceutical products he was promoting.

Over the next one and a half hours, he introduced the practitioners to six medications, which included antibiotics, painkillers, antihistamines, drugs for menstrual irregularities, and emergency contraceptives. To explain the effectiveness of these medications, he employed several mundane metaphors. He called the drug Zemiflox® (Azithromycin, a powerful antibiotic) "the king" of all antibiotics. He emphasised that the drug was so "trustworthy and effective" that practitioners could prescribe it for their clients "with their eyes closed" and say, "This king will never fail." He often used his sense of humour to reinforce the efficacies of the drugs. As a guarantee, he told the practitioners to tie the PPL's local representative Alam up with a rope if the "the king" antibiotic failed to cure any patient (later he would come to rescue Alam). Everyone laughed. No matter how humorous it was, the joke strengthened the "king" perception of the drug. However, the price (65 taka each pill)¹⁹ of the "king" drug disappointed the practitioners. Noting this, Mahbub again attempted to convince them by

¹⁹ Indeed, this price is very high when compared to another commonly prescribed antibiotic such as Ciprofloxacin, a broad spectrum powerful antibiotic, which costs 6 taka per pill.

saying that “cheap” antibiotics would not work properly. He stressed that “normal drugs” (cheap drugs) would frustrate the practitioners’ clients as they were ineffective. The frustrated clients, he warned, would then go to the city where a “fraud doctor” would give them the king drug and the patient would eventually be cured. He further mentioned that these unknown “frauds” from the city would be credited for being “the best doctor” whereas (“you”) rural practitioners would lose credibility for failing to cure the illness. This particular way of presenting the relationship between powerful antibiotics, curability, and the fame of the practitioner truly concerned me. I feared the extent to which this kind of strategy employed by Mahbub would lead to an indiscriminate use of powerful antibiotics leading to multi drug-resistant illnesses amongst poor villagers years down the line.²⁰ Mahbub also used many English terms and later provided a simpler convincing translation. This strategy presented him as a knowledgeable and legitimate person of medical knowledge, encouraging the conference participants to believe everything he told them.

At various points during Mahbub’s presentation, Alam got up to distribute notebooks, and leaflets about various medications to the practitioners. Towards the end of the training session, Alam became especially active. He distributed several gifts items (including bags, notebook, and pen) while Mahbub pleaded with them “to try the best medicines” that PPL produced. Alam’s distribution of gifts and Mahbub’s plea were two concurrent activities.²¹ Mahbub said that his company wanted to “serve this area” with the “help” of the rural practitioners. He further assured the practitioners that they would be “surprised” by the difference between the PPL drugs, and medications from other companies. Alam also distributed lunch coupons to everyone in the audience, and politely invited them to

²⁰ Anthropologists have investigated the new emergence of many infectious diseases that previously were thought to be eradicated (see, for example, Barrett, et al. 1998).

²¹ In both developed and developing countries, it is a common practice among the pharmaceutical representatives to provide gifts and various types of monetary incentives to medical practitioners in order to maximise the sales of their pharmaceutical goods (Kamat and Nichter 1998; Oldani 2004).

accompany him to a nearby restaurant. Alam reminded the practitioners that he would meet them the next day to talk about potential purchase orders for the drugs.

The practitioners, however, still had some reservations about the high prices of PPL's drugs. One practitioner expressed the opinion that their rural clients might think the practitioners greedy if they prescribed such expensive medications. Mahbub interrupted the practitioner and said, "The villagers are not foolish anymore.... they are more aware these days. If you can convince them they would understand." Alam added, "The villagers will be willing to pay more, if they know their illness would be cured." Again Mahbub said, "The better [more effective] medicines are always expensive."

In concluding the talk, Mahbub resorted to alluding to the religious and moral obligations entailed in the role of rural practitioners. He stated that the rural practitioners were "some specially selected individuals from God," adding that God did not bestow this "auspicious responsibility" of "serving people" on just anyone. God chose only certain individuals to be "doctors" to enable them to "help people." He also stressed that helping people by treating their ailments was a divine task similar to religious prayer (*ibadot*). His heart, he said, "went out to those generous practitioners" who were constantly trying to "fulfil their prayer" by helping (treating) people. I wondered how this moving conclusion would be received by the practitioners, and whether it was enough to motivate them to prescribe PPL's drugs.

All of the persuasive comments made by Mahbub and Alam showed their desperate intentions to capture the market for medicine in the area. Their heavy-handed sales techniques also showed that the main purpose for the visit had little to do with any romantic ideals of the lowland area. Mahbub had spent more than half a day travelling to this remote region, a place where other pharmaceutical companies had already established their own businesses. With this training session, Mahbub sought to invade the others' territory with his "expensive but

effective” arsenal. In order to succeed, he exploited the reputation of his company and, without providing any evidence-based proof, claimed that the medications produced by his company were more effective than medications produced by other companies. In short, the purpose for his visit was clearly to expand his company’s business by establishing a regular market in the area through the local practitioners.

Mahbub’s sales strategies also demonstrate yet another way in which the idea of hope for a cure from allopathic medicine – a theme that I observed to have motivated individuals with chronic breathlessness – is constantly reinforced for local Jalshiri people. Given the regular interactions between the local practitioners and their clients, it is easy to see how the notion of hope for a cure would transmit to the latter fairly quickly on a regular basis. This hope for a cure gives birth to—following Marx—a form of medication fetishism. In describing commodity fetishism, Marx (1976) described how a commodity under capitalism takes on an autonomous life of its own, while at the same time concealing its true characteristics as a product of human labour. By entering into a relationship with human beings and other commodities, a commodity simultaneously becomes something less than what it is (a product of human labour) and greater than what it actually is (an object that appears to have a life of its own independent of the relations of production). Fetishism transforms the relationship between individuals from the social to the material, whereas the relationship between commodities becomes transformed from the material to the social. When we encounter a commodity, because of its fetishist nature, we fail to see beyond the way it appears to us. We fail to see the mechanism of how the relations of production are concealed in the commodity.

Similarly, due to the ways in which medical information is conveyed to the rural villagers, allopathic medicine appears to them as powerful, and unbeatable. It is the curative option for their ailments. The political economy of healthcare in Bangladesh conceals the

relations of production, such that the rural villagers fail to see the broader picture of allopathic medicine. The social hierarchies that produce a lack of access to biomedical care simultaneously produce a heroic image of medicine and give birth to a belief that a better and potentially curative medicine is somewhere available to them. This concealment drives sufferers to constantly seek different kinds of medications that might possibly cure their illness.

Why do the local practitioners attend these “conferences”? Do they recognise the companies’ profiteering intention? Sajal’s story has addressed these questions too. When speaking of his medical knowledge Sajal said to me, “Because I am in this profession, I have [obviously] attended [several] trainings.” Somewhat reluctantly, he later referred to his attendance at several “conferences.” His reluctance here indicated his awareness that these conferences do not provide formal medical training. He stressed to me that he had found conferences to be “a good source of learning.” He reiterated that the people who conducted conferences, “obviously had more [medical] knowledge as they came from cities, and had secured a good position in a *medical* company [Stress is original] due to their skills and knowledge about disease.” When I attended the conference, I noticed that no one bothered to take notes, and I asked Sajal why this was so. He told me, “If anyone was meant to remember he would be able to do so without writing them down.” Of course his statement can be taken as evidence of the value of oral forms of learning in the area. Yet, my impression during this conversation was that Sajal considered participation in these conferences to be the more important aspect of these training sessions, rather than viewing them as learning exercises.

There is no doubt that the practitioners who attend these trainings do learn medical information. However, such knowledge is not the central reason for their attendance and support of these conferences. Among local village practitioners, the concept of training carried a value in itself. I once heard a practitioner in the village bazaar, who had attended a

few weeks of primary healthcare training many years ago, blaming other practitioners “for doctoring (practicing medical knowledge) without any training.” This statement together with Sajal’s emphasis on his “training” with medical representatives clearly show that the concept of “training”, in the form of attending conferences with the medical representatives, was itself a value. Faced with the challenges of prestige and legitimacy of training on the one hand, and their lack of access to such means of legitimation on the other, this group of rural practitioners turned to pharmaceutical companies for some relief. They knew these sessions were far from the training available to urban physicians. They were also aware of the business intentions of the pharmaceutical companies. Nevertheless, they seemingly accepted the pose of expert medical knowledge adopted by the medical representatives because not attending would risk delegitimising themselves, and they already faced a crisis of legitimacy.

Thus, the practitioners’ support of training sessions, and their willingness to attend involved more than just receiving supposedly new information about medicine and illnesses. Instead, these training sessions fed perfectly into the existing politics of unrecognition, in which local practitioners strove to legitimise their practice. These sessions allowed them to “claim” a form of justification for their medical practice amongst their colleagues and local clients. In other words, the whole process of the training session, including gift giving, was closely intertwined with a politics of recognition – something that the rural informal practitioners lacked. Attending those training sessions allowed the local practitioners to claim a shadow-legitimacy and an aura of recognition for their work.

Formal recognition

The presence of informal providers is not just pervasive in South Asian countries (Baru 2003; Pinto 2004); they are extensively present in Africa, the Middle East, and South East Asia (Hardon 1987; Van der Geest 1987; Van der Geest 1988; El Katsha, et al. 2006; Goodman, et al. 2007; Cross and MacGregor 2010). The ethnographic evidence I have

presented here show several critical aspects of informal services, including their close proximity and availability, their compassionate behaviour, a flexible payment system, and their individualised relationships with their clients (see also Bangladesh Health Watch 2008; Bhuiya 2009; Wahed, et al. 2012). Nevertheless, there have been several concerns voiced about the “dangerous” practices of informal services. Such concerns are centred around the unnecessary and harmful use of medications, the spread of blood-borne diseases due to unsterile equipment, and their inability to recognise the gravity of an illness (Berman 1998; Mills, et al. 2002; El Katsha, et al. 2006; Killewo, et al. 2006; Iqbal, et al. 2009).

In addition to identifying these negative aspects, scholars have also compellingly argued for the public health potential of utilising this “vast army” in a systematic way. Without ensuring a sufficient and properly functioning formal healthcare for all, removal of these informal providers would only deprive the poor, who already have limited access to medical care (Van der Geest 1988; Ahmed and Hossain 2007; Bhuiya 2009; Bloom, et al. 2009; Mahmood, et al. 2010). There have been several interventions in many countries to enhance “the appropriateness” of the work undertaken by informal providers. According to Cross and MacGregor (2010), these interventions usually concentrate upon three areas: knowledge, performance and safety, and accountability. These interventions attempt to improve the providers’ knowledge of medical practice, try to increase providers’ access to medical goods and services to enhance the safety of their work, and seek to establish a social mechanism for regulating the services of informal providers (Cross and MacGregor 2010). In an extensive review of sixteen such intervention projects, Goodman, et al. (2007) found that these interventions can bring about positive changes in the medical practices (in a biomedical sense) of informal providers by improving rates of appropriate medication usage and the quality of information they provide to their clients.

In 2009, a group of ICDDR,B researchers introduced an intervention (a method they called “social franchising”)²² with the aim of training rural untrained medical practitioners of allopathic medicine in a small sub-district of Bangladesh (Wahed, et al. 2012). The researchers named the project *ShasthyaSenas* (Health Soldiers), a form of social branding designed to appeal to attending practitioners. ICDDR,B physicians provided them with training for eleven common illnesses. At the end of the twenty training sessions, 117 out of 157 participants qualified after passing a written examination. They received crests, stickers and badges containing the logo of the Health Soldiers (*ShasthyaSenas*). This branding affiliation, the researcher believed, would work as a “spin-off effect” by increasing the number of clients and enhancing the practitioners’ reputations (Iqbal, et al. 2012). The researchers also set up “a governing committee” comprising *ShasthyaSenas*, local government, community leaders, religious leaders, beneficiaries, civil society, school teachers, health experts, and ICDDR,B representatives. The responsibilities of the committee were to motivate and support the practitioners, monitor their activities, and provide feedback on their performance. After the project ended in mid-2010, the researchers found some significant improvement in terms of increase in appropriate drug use and a reduction in the harmful use of drugs (Wahed, et al. 2012).

What happens when these types of projects end? For instance, ICDDR,B’s project ended after a year and half. What happened afterwards? In the context of Bangladesh, it is highly unlikely that the monitoring committee would continue their work of overseeing, especially when the ICDDR,B representatives were no longer involved. The actual problem with these type of interventions, as some argue, is that they do not address “the hidden transcripts” in society that label the informal medical practitioners “illegitimate” while

²² Franchising is very common in the retail commercial sectors of many countries. However social franchising differentiates itself from the profit intent by attempting to achieve social goals, which is usually employed by non-governmental organisations (Montagu 2002 cited in Wahed, et al. 2012: 31).

labelling others “legitimate” (Cross and MacGregor 2010: 1595). Instead, these interventions only reinforce those ideologies of health and illness that stem from biomedical knowledge (Hall 1997 cited in Cross and MacGregor 2010). Medical anthropologists have shed critical light on these “hidden transcripts” by identifying the hegemonic and authoritative nature of biomedicine and showing how biomedicine, being embedded in the capitalist world system, produces certain objects of knowledge (Lock and Gordon 1988; Cross and MacGregor 2010; Lock and Nguyen 2010). Therefore, interventions based on a biomedical ideological stance only reinforce certain discourses that pronounce the sole superiority and legitimacy of the experts of health – the institutionally trained biomedical practitioners.

Yet an anthropological examination of the health outcomes and life contexts of poor rural villagers demonstrates the importance of recognising the deeper politics behind these interventionist projects, and to recognise the critical importance and contributions of the informal providers. I am not, however, suggesting that we must stop any intervention and do nothing. Not intervening in the practice of informal providers leaves open the possibility of misdiagnosis, misuse of antibiotics, and other similar unintended consequences. My concern here is that we must be aware of the epistemological politics behind those interventionist intentions. For example, we must not forget that trained physicians also misdiagnose, over-prescribe and suggest unnecessary medications to their patients (Greenhalgh 1987); such practices are not restricted to untrained self-taught practitioners.

In Bangladesh, around ninety five per cent of the entire national health workforce is made up of the informal sector (Bangladesh Health Watch 2008; Bhuiya 2009). The rural people have an extremely “low utilisation rate” of seeing trained biomedical physicians (Mahmood, et al. 2010). How would the poor villagers with chronic breathlessness consult a trained physician? Numerous issues ranging from unavailability, poor interaction, high cost of consultation and medical tests, all combined with an institutionalised sense of exclusion,

hinder poor villagers from seeking treatment from a formal physician. Therefore, instead of speaking of “low utilisation” of biomedically-trained physicians by the rural poor, which implicitly shifts blame to the poor, we should probably come up with a better term, a term that also recognises the structural denial of formal medical care to the poor. To evaluate the practices of the rural self-taught practitioners, we need to look beyond just the provision and consumption of medication. We need to examine the process that spawns the negative labelling of the informal providers. We need to see how these practitioners become part of the biomedical supply chain (Cross and MacGregor 2010); and to look at their efforts to provide individualised services (Singer 1986).

It is even more important to look at these informal practitioners from a holistic perspective, as the future of healthcare systems in poor countries are less likely to have clear boundaries between expert and non-expert knowledge (Bloom and Standing 2008). Bloom and Standing state that healthcare systems in most developing countries have been exported from Europe and thus are disconnected from the actual social realities of those countries. They further point to the increasing practice of informal actors (e.g., medical technologists), corporate organisations (e.g., insurance companies), and “hybrid” organisations, which are making it easier for people to access medical information outside the formal system. They call these transformations in healthcare practices a form of “taking back of power from [the] medical professions (Bloom and Standing 2008).” In 2008, these authors edited a special issue of *Social Science & Medicine* [66(10)] titled “Future Health Systems” in which contributing authors pointed to the dynamics of “changing relationships between governments, health service providers, households and a variety of community and civil society structures (Bloom and Standing 2008: 2073).”

In sum, self-taught practitioners in Bangladesh may possess real potential to provide medical care to the poor villagers with chronic breathlessness if their practices are

institutionally recognised and incorporated. These practitioners are cognisant of the local perceptions of the illness and able to interact with their clients accordingly. Structurally, they might be in a better position to extend a routinised form of treatment, something that is common in the management of chronic illness. As an asthma sufferer myself, I have been able to manage my condition through a routine form of treatment which requires less intervention from my physician. Again, I do not wish to underplay the role of a trained physician in managing chronic breathlessness. Rather, I contend that a recognition of self-taught practitioners' practices – free from the existing epistemological bias towards the expert, the legitimate, and the trained – may function as an empirical strategy to take us one step closer to Universal Health Coverage (UHC) in Bangladesh. Though several Bangladeshi health researchers have been advocating for UHC in the country, this remains an elusive goal which the country is currently far from achieving (Bangladesh Health Watch 2012).

Chapter Seven

Conclusion

Experience of suffering in rural Bangladesh

Recently, I rang my research assistant Salil in Bangladesh for a chat and he gave me the heartbreaking news. My informant Ekram died a few months ago. With this news my thoughts were immediately taken to my many encounters with him. I remembered the first time I met him, and how he was quietly lying straight on the bed, carefully trying to avoid moving lest he became breathless. I recalled his frustrated face when he spoke of his years of labour in sludgy rice fields, and amongst dusty piles of crops. I recollected his longstanding frustrations of childlessness and his painstaking efforts to save money for his elderly life. There were also his stories of how he had been refused government relief because he was unable to pay the bribes demanded by local political elites, and of the increased financial hardships following his several visits to see a trained physician in Mymensingh. I recalled how he had tried to save his inhaler, reserving it only for emergency use, as it would be too hard for him to buy such expensive medication once it ran out. I remembered the sadness in his face when he spoke of the heightened physical weakness brought on by medications from local self-taught medical practitioners. At the same time, I could clearly recall the gratitude in his voice when he told me how local practitioners would provide him with medications on credit. As I thought back on these stories Ekram had shared with me, I realised I could not imagine the suffering that Fuli, Ekram's wife, would now be facing after the death of her husband. Having no child or relative to help her, she would now have to support herself. Her age, together with her broken ankle would mean she would be unable to get work.



Picture 15: Ekram and Fuli

Salil told me how he, along with some other villagers went to visit Ekram's house after they heard the news, something which is customary in the village. When they arrived, Fuli was grief-stricken and lamenting continuously. Salil described how the neighbouring women were trying to console her, but that she kept crying, and loudly proclaiming her grief. She kept repeating her final conversations with Ekram, who had become particularly ill in the days leading up to his death. At night, his constant wheezing had made it difficult for him to sleep and he lay awake all night. During the day, he would lie prone in his bed for hours at a time. He ate only small amounts of food until finally, on the morning of his death, he had stopped eating entirely. Two days prior, Ekram had given some money to another villager, who was going to Netrakona town for his own business, asking him to procure an inhaler. After he obtained the inhaler, Ekram had only used it once or twice before abandoning it altogether, as he did not find much improvement. When Fuli had asked him to go back to see

his physician in Mymensingh, Ekram had angrily replied, “I will not give any more money to those bastards. I buy their medicines and they don’t work (they don’t cure permanently). Why should I give them more money?” He died the following night.

The story of Ekram’s death encapsulates some of the most significant themes I have explored in this thesis. In order to tie together these themes, it is essential to take a critical medical anthropological approach (Baer 1982; Baer, et al. 1986; Morsy 1990; Singer, et al. 1990; Scheper-Hughes 1992; Singer and Baer 1995; Baer, et al. 2003). We have seen how in rural Bangladesh, social and cultural norms render chronic breathlessness a stigmatised illness. The social stigma of breathlessness, however, disproportionately affects certain people in society, particularly women, the elderly, the landless, and those who lack supportive kin networks. The discussion also shows the ways the people in Jalshiri explain chronic breathlessness with a humoral logic that associates cold, dust, and cough with one another. The sufferers’ introspections into this humoral logic explain how social inequality, economic insecurity, political powerlessness, and gender inequality force them to labour under inhumane conditions in sludge, cold, and dust.

Furthermore, the inhumane work conditions of my informants’ lives are not just the result of local power structures, dominated by the corruption of local political leaders and the informants’ inability to exercise their political and economic voice. Nor are they merely the outcome of national factors such as the state’s lack of concern over the poor infrastructure in rural areas and an institutionalised denial of care to the poor. Rather, in order to have a comprehensive understanding of their marginalisation, we need a perspective on the historic exploitation that these people experienced as a result of the long history of colonisation.

The Portuguese were the first Europeans to come to Bengal as traders, followed later by the Dutch, French and English. All of them had a particular interest in the eastern part of

Bengal because of its famous cotton textile industry, something that was “among the greatest industries of the world” (Hartmann and Boyce 1983: 13). The British transformed their role from traders to ruler through a decisive victory against the Muslim ruler in 1757 as a result of a conspiracy plot with the ruler’s close companions. During the course of colonial rule, the British destroyed the Bengali textile industry by imposing fines, imprisonment, prohibitions, and duties in order to eliminate competition that threatened British industries and to facilitate the extraction of wealth from the region (Dutt 1902; Dutt 1904). This colonial extraction of wealth continued for two hundred years, which contributed to England’s prosperity while making the Bengal poorer day by day through the systematic destruction of its manufacturing industries.

In 1947, British rule ended and India and Pakistan emerged as two independent states. The religious identity of Muslims and Hindus played a critical role in the formation. The people of the eastern part of Bengal (today’s Bangladesh), mostly populated with Muslims, became part of Pakistan, a Muslim-majority country. Soon the people of East Pakistan realised that they had shifted from one colonial ruler to another. During the formation of Pakistan, most of the influential political leaders in national politics were from West Pakistan. Consequently, the West Pakistanis ruled Pakistan from the capital of Karachi, in the West. The West Pakistani rulers dominated East Pakistanis in all spheres of life. The people of East Pakistan were not allowed to exercise any political power to govern themselves. The West Pakistani rulers appointed themselves to most of the best jobs. The people of East Pakistan had to purchase commodities from West Pakistan at a higher price and the revenues collected from East Pakistan were mostly used for the development of the West, not the East (Sen Gupta 1974).

The people of East Pakistan demanded greater autonomy and their leader Bangabandhu Sheikh Mujibur Rahman won a landslide victory in a national election, which

would have made him the prime minister of all Pakistan, both East and West. The rulers of then-West Pakistan said, “Majority alone doesn’t count in national politics” (Lifschultz and Bird 1979: 203) and refused to transfer power. Instead its army started a massacre on 26 March 1971, indiscriminately killing civilians of East Pakistan, leading to a civil war that lasted for nine months. Three million civilians were killed, over 250,000 women were raped and over 20 million Bengalis became refugees as a result of this brutal civil war (Zaman 2005). On 16 December 1971, the genocide ended and a new country, Bangladesh, was born. Bangladesh was born as one of the poorest countries in the world after several hundred years of wealth depletion.

As much as today’s dependency on inhumane agricultural labour conditions in rural Bangladesh is connected with local and national factors, they are also products of the global political economy of colonial exploitation in the region and the aftermath of postcolonial war. Therefore, when my informants explained their experience of breathlessness by connecting them with their long hours of work in sludge, cold, and dust, we must remember all of the local, national, and global mechanisms that resulted in this reality of suffering.

I have also detailed how my informants possess a strong sense of hope that modern medicine will offer them a cure. We need to interpret this hope in terms of its connections with the hegemonic nature of modern medicine, which constantly promotes an indispensable image of curability rather than regular management of the condition (Kothari and Mehta 1988; Gaines and Davis-Floyd 2004; Singer 2004). As an imported European cultural practice, modern medical systems also fail to recognise the social realities of the local people in South Asian cultures (Bloom and Standing 2008). We need to realise that under circumstances of extreme deprivation, it is exceedingly difficult for many people – my informants included - to obtain medications. It is impossible for them to continuously consume medications on a regular basis, as is required in the regular management of chronic illness. Additionally, my

informants did not have a formal physician nearby. They had to rely on local self-taught medical practitioners whose social status, as I have described, was also politicised in the context of a formal medical system which favoured the formal physicians. Formal physicians, however, tend to reside in urban areas in Bangladesh. This disinterest in extending medical care to those people in marginalised socio-economic circumstances, and those who live in remote locations is probably due to the fact that treating these groups brings less prestige and minimal monetary benefits. By contrast, working in urban clinics and hospitals offers greater financial gains and career prospects (see also Baer 1989; Gaines and Davis-Floyd 2004). Observing these broader aspects of the political economy of healthcare in Bangladesh is useful in understanding how chronic breathlessness is situated in relation to the individual, social, and political realities of my informants' lives (Scheper-Hughes and Lock 1987).

In a special issue of *Social Science & Medicine* on anthropology and chronic illness, editors Suzanne Heurtin-Roberts and Gay Becker (1993: 281) define chronic illness as “health conditions that can be managed but not cured” and “have ongoing or periodic symptoms that *interfere* with daily life” (emphasis added). To what extent did chronic breathlessness “interfere” in the day-to-day lives of my informants? The stories I have detailed throughout this thesis clearly show how my informants would relay their experience through foregrounding their marginalised socio-economic circumstances, oftentimes dismissing the presence of their illness.

Willem Van Schendel, a well-known anthropologist, has closely observed life in rural Bangladesh (see for example, Van Schendel 1981; Van Schendel 1986; Van Schendel 1991). He writes,

The lush Bangladesh countryside has the dubious distinction of being home to tens of millions of the world's most desperately poor people... When survival becomes the main concern of an entire society, almost all social relations take on a new meaning. Individuals and groups in

search of ways to ensure their own social and physical survival will attempt to use existing relations in new ways for this new end. As more and more social behaviour becomes 'survival-oriented', the struggle for survival is waged in such diverse arenas as kinship networks, religious congregations, patronage systems, labour relations, sexual politics and ethnicity. For the desperately poor almost all behaviour tends to become part of one huge survival strategy – and *life itself* becomes little more than survival (1986: 41 emphasis added).

Van Schendel then goes on to emphasise the profound depths of the poverty in Bangladesh, saying, "today no other Asian society is experiencing such overwhelming deprivation with so little prospect of improvement (Ibid.,: 52). When studying such poverty-stricken conditions, it is easy to fall into the trap of thinking of the rural poor as passive victims only, which would be an erroneous conclusion. Van Schendel has discussed how the rural poor attempt to deal with their marginalised circumstances through several economic, social, political, demographic, and networking survival strategies. Some of these strategies include limiting consumption of necessary item such as food and clothing, attempting to increase agricultural output, trying other means of income unrelated to land such as begging or handicraft, migrating to other areas as daily labourer, manipulating the household composition, engaging with political factionalism in the village and frequently changing alliances to maximise gain, and trying to produce many children especially sons who join the labour force at an early age. When compared to the situation of a few decades ago, the use of these strategies has increased extensively but their effectiveness has been reduced (Van Schendel 1986).

The stories of my informants demonstrate the brutal faces of poverty and extreme deprivation. Many of their attempts to cope with hardship, such as migrating as a daily labourer or borrowing from others, often resulted in self-defeating experiences. Their stories also suggest that only rarely were they able to consider their chronic breathlessness the most pressing dilemma in their daily lives. Rather their marginalised social situation characterised by a chronic presence of poverty, frustration, and disappointment dominated their everyday world. I do not mean to suggest that there were no positive changes in their experience of

marginalised social situations. Both marginality and survival strategies are malleable (see also Van Schendel 1986). Thus, even if changes were temporary, my informants did experience positive changes, such as at the end of a successful harvesting period. Nor do I wish to claim that the experience of breathlessness was entirely diluted by the experience of frustration and disappointment in the lives of my informants. The lived experience of illness was periodic, and there were many ups and downs in the severity of the condition. Anthropological literatures on chronic illness has explored how these fluidities not only shape people's perceptions of suffering, but also characterise the self-identities of the sufferers (Estroff 1993; Honkasalo 2001; Van Dongen and Reis 2001; Manderson and Smith-Morris 2010a).

In contributing to the anthropological debate on chronic illness, I argue that it might not always be the case that individuals' experience of chronic illness profoundly impacts their self-identities. For my informants, it was their lived experience of marginality as a social condition that played a critical role in shaping their self-identity, rather than their experience of living with chronic breathlessness. In other words, my informants did not experience chronic breathlessness as chronic and this was not because of the periodic nature of the illness. It was because the routine suffering of breathlessness tended to be immersed in other forms of routine suffering that played a more dominant role in their social lives. The experience of living in marginalised social circumstances was so overarching that the experience of breathlessness appeared to them only as an episodic intensification or additional layer of suffering. That is to say, the experience of social marginalisation routinely transcended their experience of chronic breathlessness in a way that the former appeared to them as the most important issue at stake in their lives. Ekram's story and his subsequent death serve as stark reminders of the extreme vulnerability of those who suffer from chronic breathlessness in rural Bangladesh. Unless we can address the overwhelming social marginalisation of these

sufferers, and how this interferes with their ability to cope with their illness, there is little hope that the stories described in this thesis will end any differently.

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Appendix A										
INFORMANTS' PROFILE										
Y= Yes N= No Bam= Bamboo Bio= Biomedicine										
9	8	7	6	5	4	3	2	1	SL No	
09SMR	08SMR	07SFR	06SFR	05SFR	04SFR	03SFR	02SFR	01SFR	Code	
Uttam	Roni	Rabeya	Hasna	Humayra	Rokeya	Rahela	Sushoma	Joya	Name	
R	R	R	R	R	R	R	R	R	Location R/U	
H	H	I	I	I	I	I	H	H	Religion	
M	M	F	F	F	F	F	F	F	Sex	
44	24	60	44	40	62	57	65	48	Age	
M	S	W	M	M	W	M	M	M	Marital status	
10	HSC	Nil	Nil	5	5	2	Nil	Nil	Education	
Pond, nonsan	Pond, San	Pond/nonsan	Pond, nonsan	Pond, nonsan	Pond, nonsan	Nil	River, nonsan	Tube well, San	Shower/latrine	
Nil	Nil	No	No	Yes	Nil	Nil	Nil	Nil	Land ownership	
Rent	Father	No	Hus/govt	No	Self	Hus	No/govt	Husband	House ownership	
Tin-Tin-Mud-2	Tin-Tin-Brick-4	Tin-bam-bam-2	Tin-bam-mud-1	Tin-bam-mud-3	Tin-bam-mud-2	Bam-bam,mud3	Bam-bam-mud-1	Tin-Tin-Mud-2	House Type [Shade-Wall-Floor-room no]	
Business	Business	Nil	House wife	Nil	Nil	Nil	House wife	House wife	Occupation	
4000	5000	Nil	Nil	Nil	1500	Nil	Nil	Nil	Expense p/m	
4	4		2	6	6	7	3	3	Family member	
Y	N	Y	Y	Y	Y	Y	Y	Y	Smokeless Tobacco	
Y	Y	N	N	N	N	N	N	N	Smoking tobacco	
Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Current Medicine	
Y	Y	Y	Y	Y	Y	N	Y	Y	Folk Medicine	

18	17	16	15	14	13	12	11	10	SL No
18SFR	17SMR	16SMR	15SMR	14SFR	13SMR	12SMR	11SMR	10SMR	Code
Aleya	Sontosh	Sitesh	Ekdil	Shokhina	Rakhal	Marfat	Nanda	Sukesh	Name
R	R	R	R	R	R	R	R	R	Location R/U
I	I	H	I	I	H	I	H	H	Religion
F	M	M	M	F	M	M	M	M	Sex
44	80	17	75	25	48	72	70	29	Age
W	W	S	M	M	M	W	M	M	Marital status
Nil	2	6	5	2	4		5	Nil	Education
Pond, non-san	Tube, san	Pond, non-san	Pond, san	Pond, non-san	River, non-san	Tube well, san	Pond, non-san	River, non-san	Shower/latrine
Nil	Yes	No	Yes	Nil	Nil	Nil	Nil	Nil	Land ownership
No	Yes/govt	No	Yes	Yes	No	Yes	Yes/govt	Yes/govt	House ownership
Tin-bam-mud-1	Tin-Tin-mud-2	Bam-bam-mud-1	Bam-bam-mud-2	Tin-bam-mud-2	Bam-bam-mud-1	Tin-tin-mud-3	Tin-bam-mud-1	Tin-mud-mud-2	House Type [Shade-Wall-Floor-room no]
Nil	Nil	Labourer	Nil	Seas laborer	Labourer	Nil	Business (ill)	labourer	Occupation
3000	5000	6000	4000	1500	5000	5000	5000	2500	Expense p/m
5	9	11	4	3	5	7	6	3	Family member
Y	Y	N	Y	Y	Y	Y	Y	Y	Smokeless Tobacco
N	Y	Y	Y	N	Y	Y	Y	Y	Smoking tobacco
Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Current Medicine
Y	Y	Y	Y	Y	Y	Y	Y	Y	Folk Medicine

28	27	26	25	24	23	22	21	20	19	SL No
28SFU	27SMU	26SFU	25SFU	24SFU	23SMU	22SMU	21SMU	20SFR	19SFR	Code
Mukti	Shamim	Konabibi	Momtaz	Tisha	Solaiman	Anwar	Bashir	Julekha	Sahara	Name
U	U	U	U	U	U	U	U	R	R	Location R/U
I	I	I	I	I	I	I	I	I	I	Religion
F	M	F	F	F	M	M	M	F	F	Sex
40	28	55	70	21	59	45	43	36	60	Age
M	S	W	M	S	M	M	M	M	W	Marital status
MA	MA	4	5	Bcom	HSC	5	SSC	Nil	Nil	Education
Tap, San	Tap, San	Tap, san	Tap, San	Tap, San	Tap, San	Tap, San	Tap, san	Pond, non-san	Pond, non-san	Shower/latrine
Yes	Nil	Nil	Nil	Nil	Yes	Nil	Nil	Nil	Nil	Land ownership
Yes	Yes/P	Yes	Yes	Yes/P	Yes	No	No	Yes/govt	No	House ownership
Brick	Tin-brick-brick-4	Brick	Brick	Brick-brick-brick-3	Brick-brick-brick-4	Brik-brick-brick-2/ren	Tin-brick-brick-2/rent	Tin-bam-mud-2	Bam-bam-mud-2	House Type [Shade-Wall-Floor-room no]
Service	Student	H Wife	H wife	Student	Retired	Car repairer	Driver	Labourer	Labourer	Occupation
30000	8000	Nil	Nil	30000	25000	20000	13000	6000	2500	Expense p/m
4	5	6	4	4	3	12	4	6	5	Family member
N	N	Y	Y	N	Y	Y	N	Y	Y	Smokeless Tobacco
N	Y	N	N	N	Y	Y	Y	N	Y	Smoking tobacco
Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Current Medicine
N	N	Y	Y	N	N	Y	Y	Y	Y	Folk Medicine

37	36	35	34	33	32	31	30	29	SL No
37SMU	36SMU	35SMU	34SMU	33SMU	32SMU	31SFU	30SMU	29SFU	Code
Shahidul	Nazim	Osman	Aolad	Samcudin	Samsul	Koruna	Apu	Rokeya	Name
U	U	U	U	U	U	U	U	U	Location R/U
I	I	I	I	I	I	H	I	I	Religion
M	M	M	M	M	M	M	M	F	Sex
38	50	32	65	46	54	60	32	60	Age
M	M	M	M	M	M	W	S	W	Marital status
Nil	Nil	Nil	10	Nil	MS	Nil	BA	Nil	Education
Tap/San	Pond/san	Tube well/san	Tube well/san	Tap/San	Tap/san	Tap, San	Tap, San	Tap, San	Shower/latrine
No	Yes	No	No	Yes	Yes	Nil	Nil	Nil	Land ownership
No	Yes	No	Yes	Yes	Yes	Yes	Nil	Nil	House ownership
Tin-tin-mud-1	Tin-tin-mud-2	Tin-brick-brick-1	Tin-brick-brick-2	Tin-tin-mud-3	Building-3	Tin-brick-brick-3	Brick-3/rent	Tin-brick-brick-2/rent	House Type [Shade-Wall-Floor-room no]
Business	Farmer	Business	Business	Farmer	Service	House wife	Service	House Wife	Occupation
4000	20000	15000	22000	10000	6000	8000	40000	Nil	Expense p/m
1	5	5	6	7	6	6	5	6	Family member
Y	Y	Y	Y	Y	N	Y	N	Y	Smokeless Tobacco
Y	Y	Y	Y	Y	Y	N	Y	N	Smoking tobacco
Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Bio	Current Medicine
Y	Y	N	N	Y	Y	N	N	Y	Folk Medicine

44	43	42	41	40	39	38	SL No
44SMU	43SMU	42SMU	41SFU	40SMU	39SMU	38SMU	Code
Jubayer	Kamal	Shahed	Rahela	Mosarof	Manik	Ali	Name
U	U	U	U	U	U	U	Location R/U
I	I	I	I	I	I	I	Religion
M	M	M	F	M	M	M	Sex
27	50	80		82	81	60	Age
S	M	W	M	W	W	M	Marital status
BSS	BA	SSC	SSC	HSC	5	MA	Education
Tap/San	Tap/San	Tube/San	Tap/San	Tube/San	Tap/San	Tap/San	Shower/latrine
No	Yes	Yes	Yes	Yes	No	Yes	Land ownership
No	Yes	Yes	Yes	Yes	No	Yes	House ownership
Brick-2	Brick-4	Brick-2	Brick-4	Tin-brick-brick-3	Tin-brick-mud-2	Tin-brick-mud-3	House Type [Shade-Wall-Floor-room no]
Student	Service	Retired	House Wife	Retired	Security Guard	Retired	Occupation
15000	40000	30000	35000	Nil	17000	18000	Expense p/m
4	4	5	4	5	6	6	Family member
N	N	Y	N	Y	Y	Y	Smokeless Tobacco
Y	Y	Y	N	Y	N	Y	Smoking tobacco
Bio	Bio	Bio	Bio	Bio	Bio	Bio	Current Medicine
Y	N	Y	N	Y	N	N	Folk Medicine

Ethics application Reference: 5201000573- Final Approval

1 message

Ethics Secretariat <ethics.secretariat@mq.edu.au>

Fri, Jun 18, 2010 at 11:38 AM

To: lisa.wynn@mq.edu.au

Cc: Anupom Roy <anupom.roy@mq.edu.au>

Dear Dr Wynn

Re: Biomedicine and chronic illness: negotiating knowledge and health in rural Bangladesh

Thank you for your recent correspondence. Your response has addressed the issues raised by the Human Research Ethics Committee and you may now commence your research. This approval is subject to the below mentioned condition:

1. Please forward the names and contact details of the research assistants when these details are available.

The following personnel are authorised to conduct this research:

Dr Lisa Wynn – Chief Investigator/Supervisor

Mr Anupam Roy- Co Investigator

Please note the following standard requirements of approval:

1. The approval of this project is conditional upon your continuing compliance with the *National Statement on Ethical Conduct in Human Research (2007)*.

2. Approval will be for a period of five (5) years subject to the provision of annual reports. Your first progress report is due on 18/06/2011.

If you complete the work earlier than you had planned you must submit a Final Report as soon as the work is completed. If the project has been discontinued or not commenced for any reason, you are also required to submit a Final Report for the project.

Progress reports and Final Reports are available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms

3. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Committee to fully re-review research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).

4. All amendments to the project must be reviewed and approved by the Committee before implementation. Please complete and submit a Request for Amendment Form available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms

5. Please notify the Committee immediately in the event of any adverse effects on participants or of any unforeseen events that affect the continued ethical acceptability of the project.

6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the University. This information is available at the following websites:

<http://www.mq.edu.au/policy/>

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/policy

If you will be applying for or have applied for internal or external funding for the above project it is your responsibility to provide the Macquarie University's Research Grants Management Assistant with a copy of this email as soon as possible. Internal and External funding agencies will not be informed that you have final approval for your project and funds will not be released until the Research Grants Management Assistant has received a copy of this email.

If you need to provide a hard copy letter of Final Approval to an external organisation as evidence that you have Final Approval, please do not hesitate to contact the Ethics Secretariat at the address below.

Please retain a copy of this email as this is your official notification of final ethics approval.

Yours sincerely

Dr Karolyn White

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